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TITLE: Quality of Breast Cancer Care: The Role of Hispanic Ethnicity, Language, and Socioeconomic Position

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**14. ABSTRACT**

Using data from a population-based sample of breast cancer patients in Los Angeles County. Their physicians, and neighborhood data, our goal is to examine the relative importance of ethnicity, language, and socio-economic position, and how they relate to structure, process, and outcomes of breast cancer care. In neighborhood-level analyses, Hispanic neighborhood was statistically significantly associated with numerous measures of socio-economic resources and acculturation. In patient-level analyses, we found evidence of socio-economic disparities in breast cancer decision-making and treatment: 1) Low-income was a barrier to breast reconstruction discussion and receipt; 2) Physician-patient discussion of treatment outcomes was correlated with patient satisfaction; 3) Older and lower income women were at higher risk of not participating in decision-making. Ethnic differences appeared to be explained by socio-economic status in these analyses. In provider-level analyses: 1) Physicians reported high career satisfaction levels but were least satisfied with time spent with patients; 2) Explicit financial incentives tied to performance on quality measures were reported at modest rates, primarily associated with HMO settings; 3) Most frequent reports of financial incentives to perform more services were among medical oncologists performing office-based chemotherapy and growth factor injections; 4) Treating more limited English-proficient patients was associated with decreased physician satisfaction with time spent with patients; 5) Greater intensity of interpreter service use ameliorated some of this dissatisfaction.

**15. SUBJECT TERMS**
Breast cancer, quality of care, disparities, neighborhood, financial incentives, language

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**2007 ANNUAL SUMMARY REPORT REPORT: DAMD17-03-1-0328, POST-DOCTORAL AWARD "QUALITY OF BREAST CANCER CARE: THE ROLE OF HISPANIC ETHNICITY, LANGUAGE, AND SOCIOECONOMIC POSITION," (DIANA TISNADO, PH.D., P.I.; KATHERINE L. KAHN, FACULTY MENTOR)**

**INTRODUCTION**:

Socioeconomic position (SEP) refers to a range of dimensions that describe absolute and relative position in society including not only income and education, but also poverty, deprivation, wealth, occupation and social status.[1] Studies have found powerful relationships between SEP and various health indicators, including breast cancer outcomes.[2] Additionally, omitting important effects at the contextual or neighborhood level can be problematic, resulting in misleading findings.[3] The specific aims of this DOD-funded study are to 1) enrich an existing, clinically extensive survey data set collected from a diverse population-based sample of women in Los Angeles County with breast cancer with data from the Year 2000 Census; 2) examine the relative importance of ethnicity, language, SEP and how they relate to the structural characteristics of settings in which women receive care, the care women do and do not receive, and, ultimately, to patient outcomes, particularly for the population-based sample of Hispanic and non-Hispanic white women with breast cancer; 3) to inform strategies to address racial and ethnic, linguistic, and socioeconomic disparities in breast cancer care. This study is observational in design, and will build upon an existing dataset from a cohort of women with newly diagnosed breast cancer (Los Angeles Women's Health Study (LAWHS), funded by the NCI, RAND IRB #k0048-98-01, current approval through 12/14/07), supplementing the already rich information about quality and outcomes of care with neighborhood level data from the Year 2000 census, as well as with enriched data regarding the structure of care that have been collected from physicians who care for women with breast cancer (Impact of Structure on Quality of Breast Cancer Care, funded by the California Breast Cancer Research Program, (CA BCRP), UCLA IRB#G01-11-093B, current approval period 8/22/2006 – 8/21/07, renewal pending).

The ultimate goal of the proposed work is to inform our understanding of racial and ethnic disparities in breast cancer care and the contribution of SEP and linguistic barriers, particularly for the growing population of Hispanic women. [4] This work has the potential to contribute to the body of knowledge for understanding why certain cohorts of women with breast cancer fare worse than others, and additionally to inform strategies to improve access to and quality of care for all women with breast cancer. The current UCLA IRB approval period for this project is from 04/18/2007 to 3/06/2008.

Our specific aims have remained unchanged and we have made substantial progress. We have previously been granted one project extension, which was requested due to a one year-long delay in start date associated with difficulties obtaining consistent IRB approvals from both UCLA and the Department of Defense. We received official approval to begin work, July 16, 2004. In June of 2007, we requested and were granted a second no-cost extension. There were several factors that contributed to this request. 1) To examine the key study questions regarding the relationship between neighborhood-level characteristics and receipt of key processes of care by women with breast cancer, key study analyses depend upon linkage of the neighborhood and physician level data to the patient level survey data (from the NCI-funded Los Angeles Women's Health Study of which Dr. Tisnado's mentor, Katherine Kahn, is the principal investigator). Preparation of the patient survey data set and its key variables for the proposed DoD study, particularly patient quality of care and patient outcome variables, has taken longer than planned, such that data were not ready for the proposed linked analyses until now. 2) During the past year, Dr. Tisnado was in the process of an international adoption. Placement occurred nearly a year sooner than originally anticipated, resulting in her taking an earlier-than-expected three-month parental leave. 3) During the past year, an important co-investigator on the patient study and the statistical programmer working on the DoD-funded study unexpectedly quit to work in the private sector.

As stated above, the second no-cost extension request and associated revised Statement of Work, which extends Year 3 tasks over an additional year, were approved on June 11, 2007. A copy of the approved revised Statement of Work can be found in the Appendix.

**BODY**:

The tasks associated with Months 1-18 of the original Statement of Work have been completed with one exception: planned manuscripts describing findings regarding geographic distributions of patients by race/ethnicity, language skills, and individual and neighborhood-level SEP factors including distance to health care providers have not been completed. One manuscript describing such distributions and how they relate to survey response, discussed in the 2006 report, is in preparation [5].

Census tract-level data: We have obtained Year 2000 Census Summary File 4 data,[4] including detailed population and housing data collected from a sample of the population with the census long-form. Study variables have been defined based on the literature,[1, 6] previous work of colleagues, and based upon their statistical univariate distributions and the correlations among the census variables and with key patient-level variables. We have derived the census tract-level study variables of interest from the original Census 2000 variables. These include variables measuring racial/ethnic composition (i.e., percentage of individuals in each census tract that are non-Hispanic white, non-Hispanic black, Hispanic, other); socio-economic resources (i.e., percentage of population living under the Federal Poverty Level, percentage of the adult population with less than four years of high school, percentage of adult population with less than nine years of education, percentage of population in the labor force that is unemployed); and acculturation (i.e., percentage of the population that is foreign-born, that has citizenship, and that is from a linguistically isolated household (i.e., no one in household reports speaking English well or very well). More detailed definitions of these variables were presented in previous reports. As an additional measure of neighborhood level socio-economic resources, we also plan to use derive and use variables measuring percentages of the population with various levels of occupational status.

Geo-coding of patient and physician data: Patient and health service provider addresses have been mapped to Los Angeles census tracts. Census tract-level data have been merged with patient-level *registry* data. Analyses have been conducted using this patient registry and neighborhood-level dataset to examine associations between neighborhood-level variables, patient-level variables, and variables associated with the quality of hospitals in which women with breast cancer were initially diagnosed and treated, partially addressing Study Hypothesis 3, that Hispanic women reside in communities of lower socio-economic position.

Analyses described in our previous report examined bivariate associations between these variables and characteristics of breast cancer patient hospital of definitive diagnosis as reported by Los Angeles County Registry data. Specifically, we examined associations with hospital characteristics believed to be associated with quality of breast cancer care, under the assumption that hospital quality could be examined as a marker for overall quality of health care provider to which patients from various neighborhood types had access. Associations were examined using Chi Squares and GLM. Results indicated that non-white patients were more likely to reside in areas with fewer socio-economic resources and lower rates of acculturation. Patients from neighborhoods with fewer socio-economic resources (i.e., patients from high poverty areas, undereducated areas, and areas with lower acculturation) were also statistically significantly more likely to be diagnosed in hospitals with high levels of teaching involvement, but were less likely to be diagnosed in hospitals with high volumes of breast cancer patients, which has been found to be associated with the quality of breast cancer care [7]. After adjusting for clustering of patients within hospitals, these associations remained statistically significant. Associations with the presence of an American College of Surgeons cancer program were not found to be statistically significant after adjusting for clustering of patients within hospital.

Of interest to the study questions is the concept of ethnic (Hispanic in this case) neighborhoods [8]. Previously, we had used ethnic group percentage in its continuous form. During the past year, we began the process of exploring definitions of "Hispanic neighborhoods," examining various cutoffs for creating an indicator variable of Hispanic neighborhood for the purpose of examining how quality of breast cancer care varies for Hispanic breast cancer patients residing in Hispanic neighborhoods as compared with other neighborhood types. We examined the univariate statistics associated with the percent Hispanic variable, finding that the variable was measured for the 2424 women with Rapid Case Ascertainment data from the County Registry. The variable has a mean of 31.2% and a standard deviation of 26.1% (min=0, max=99.4) We examined three definitions of High Hispanic areas, with cutoffs at 1) the median percentage Hispanic (>22% of population in census tract is Hispanic) with 1210 study patients residing in such tracts, 2) the mean (>31% of population in census tract is Hispanic) with 977 study patients residing in such tracts, and 3) majority Hispanic (>50% of population in census tract is Hispanic; close to the 75th percentile for percentage Hispanic) with 571 study patients residing in such tracts. In bivariate logistic regression, the odds of a Hispanic study patient residing in a Hispanic neighborhood was close to 6 for each definition of Hispanic neighborhood (O.R.=5.9 for the definition based on the mean, 5.7 for the definition based on the median, and 6.3 for the definition based on the majority, $p<0.0001$ for each). Next we examined the bivariate associations between Hispanic neighborhood defined each of the three ways and the census tract-level variables representing measures of socio-economic resources and acculturation using ANOVA for continuous covariates and Chi Squares for dichotomous categorical covariates. Each of the three definitions of Hispanic neighborhood was statistically significantly associated with all measures of socio-economic resources and acculturation with p-values of 0.01 or smaller. As a next step, Hispanic neighborhoods may be further classified as those with greater or fewer socio-economic resources. With this in mind, it is likely that we will use the definition of Hispanic neighborhood based on the median in our planned multivariate analyses, since this definition results in a balanced sample size of study patients residing inside and outside of this neighborhood type. However, sensitivity analyses will be performed on future analyses to test the impact of varying the definition.

Analysis of patient and physician data: Baseline and follow-up survey data for the cohort of non-Hispanic white, and Hispanic English and Spanish-speakers have been collected, and we have begun the process of examination of distributions and other univariate statistics for key patient-level survey variables. Aspects of the proposed work have required coordination with LAWHS patient study activities and methodologies, most importantly with respect to defining the outcome measures of interest, i.e., explicit quality of care scores and scores of patient ratings of physicians. Development of these measures has now been completed and analyses are underway addressing Study Hypothesis 1, that receipt of quality care differs by race/ethnicity and language group, controlling for other factors. Analyses of survey data collected from the *physician* survey have also been ongoing to examine physician demographics, use of interpreter services, and barriers and facilitators to providing quality care.

We are engaged in several manuscripts including published manuscripts: "Symptoms after breast cancer treatment: are they influenced by patient characteristics?" [9], and "Symptom management after breast cancer treatment: is it influenced by patient characteristics?" [10]; manuscripts under review: "The structural landscape of the health care system for breast cancer care in Los Angeles County:  results from a physician survey," [11] "Who receives breast reconstruction post-mastectomy?" [12], "Who is at risk for being excluded from the decision-making process for breast cancer treatment?" [13], and "Use of interpreters by physicians treating women with breast cancer:  results from the Los Angeles Women's Health Study," [16]; and, in preparation regarding: neighborhood impact on survey participation [5]; physician reports of financial incentives [14, 15], and physician symptom management.[17]

**PATIENT-LEVEL ANALYSES**:

To date, patient-level analyses have involved analyses of selected measures of health status and process of care (e.g., self-reported symptom burden, having symptom needs met, discussion regarding post-mastectomy

reconstruction for eligible patients, and overall patient ratings of quality of care) and how they vary with patient characteristics such as race/ethnicity, English-proficiency, and age, controlling for clinical variables such as stage and comorbidities. These analyses all involved use of the cohort of patients who participated in the baseline and follow-up in-depth patient survey in either English or Spanish (n=1219)(315 for those patients eligible for breast reconstruction). Approximately 50% of responding Hispanic patients   completed the survey in Spanish and the remainder completed the survey in English.  Stage at diagnosis was obtained from the SEER registry. All regressions are adjusted for clustering within hospital registry associated with the diagnosis, and were also weighted for non-response.

With respect to **patient symptoms and symptom management**, we found almost half (46%) of study survey participants had at least one severe symptom (any of the following: nausea/vomiting, arm problems, hot flashes, vaginal dryness, difficulty sleeping) that interfered with her daily functioning or mood. analyses to study the relationship between patient characteristics and symptom prevalence. Multivariate analyses were conducted using a two-part model.  First, we used logistic regression to predict women experiencing any symptoms severe enough to influence function or mood during the last six months.  Next, we used linear regression to predict the number of symptoms experienced.  We also conducted separate logistic regressions predicting each of the five individual symptoms.  Model covariates were the same as the model predicting experience of any of the aggregate five symptoms.

Multivariate analysis controlling for patient characteristics and treatment showed that older (OR= 0.90; P<0.000), black (OR= 0.50; P<0.000), Hispanic Spanish-speaking (OR= 0.37; P<0.000), women were *less* likely to report severe symptoms than other women.  Number of comorbid conditions (OR= 1.21; P<0.000) and receipt of chemotherapy (OR= 1.48; P=0.040) were positively associated with reporting symptoms. [9] However, additional multivariable, logistic regression analyses revealed that black women (OR=3.61, 95% CI: [1.57, 8.31]), and Spanish-speaking Hispanic women (OR=2.69, 95% CI: [1.22, 5.94]) were significantly *more* likely than white women to report an unmet need (defined as having had at least one severe symptom for which a woman did not receive the help she wanted. More black and Hispanic women compared to white women cited the doctor not thinking treatment would benefit her (P=0.02), not appreciating how much the problem bothered her (P=0.03), not knowing about treatments (P<0.0001), or insurance/cost barriers (P=0.009) as reasons for her unmet need.[10] Thus, despite lower rates of reported symptoms, we found evidence of the persistence of racial disparities in the health care system with respect to treatment of reported symptoms. Two published manuscripts associated with the work addressing **patient symptoms and symptom management** are attached under Appendix II. [9, 10]

Next, bivariate and multivariable logistic regression models were used to estimate the impact of demographic, socio-economic and other factors on receipt of physician-patient **discussion of and use of breast reconstruction**. Of 315 post-mastectomy women, 81% reported physician-patient discussion and 27% reported use of breast reconstruction. Bivariate analyses shown in Table 1 below indicate that **older** women (>70 years), **English-speaking Hispanic** women, and **black** women were less likely to have had a discussion about reconstruction. Discussion also varied significantly as a function of income, employment status, number of comorbidities, living with a companion, and hospital characteristics. Women older than 70 and English-speaking Hispanics were also less likely to report actual receipt of breast reconstruction.

**Table 1:  Descriptive Statistics of Women with Mastectomy, Discussion of Breast Reconstruction (yes or no), and Breast Reconstruction (yes or no)**

|  | Mastectomy (n = 315) | Discuss (Yes) (n = 245) | Discuss (No)[i] (n = 57) | Reconstruct (Yes) (n = 84) | Reconstruct (No)[i] (n = 231) |
|---|---|---|---|---|---|
| Age (years) |  |  | ** |  | *** |
| 50 – 59 | 30% | 33% | 17% | 52% | 22% |
| 60 – 69 | 32% | 34% | 25% | 28% | 34% |

| | | | | | |
|---|---|---|---|---|---|
| > 70 | 37% | 33% | 58% | 21% | 43% |
| Ethnicity | | | * | | ** |
|  White | 58% | 61% | 45% | 72% | 53% |
|  English speaking Latino | 13% | 10% | 24% | 5% | 16% |
|  Spanish speaking Latino | 12% | 12% | 6% | 13% | 11% |
|  African American | 12% | 11% | 17% | 3% | 15% |
|  Other | 6% | 6% | 8% | 7% | 6% |
| Education | | | | | ** |
|  Less High School | 16% | 13% | 22% | 36% | 20% |
|  High School Graduate | 30% | 29% | 34% | 25% | 31% |
|  Some College | 27% | 30% | 19% | 36% | 24% |
|  College Grad or more | 27% | 28% | 25% | 35% | 24% |
| Income | | | *** | | *** |
|  < $20,000 | 32% | 25% | 59% | 7% | 41% |
|  $20,001 to $40,000 | 19% | 19% | 16% | 15% | 21% |
|  > $40,000 | 49% | 56% | 25% | 78% | 39% |
| Health Insurance (y) | 94% | 95% | 92% | 100% | 92%* |
| Employment (y) | 24% | 28% | 11%* | 44% | 16%*** |
| Physical SF-12[1] | 49.4 (9.9) | 50.2 (9.2) | 49.4 (9.4) | 50.9 (10.0) | 48.9 (9.9) |
| Mental SF-12 | 52.8 (10.3) | 52.9 (10.1) | 52.9 (10.5) | 52.9 (10.3) | 52.7 (10.3) |
| Number of Comorbidities[2] | | | ** | | ** |
|  None | 18% | 20% | 5% | 25% | 15% |
|  1 – 2 | 47% | 20% | 41% | 52% | 45% |
|  > 3 | 35% | 29% | 53% | 23% | 40% |
| Body Mass Index | 26.7 (5.3) | 26.9 (5.2) | 25.3 (4.8) | 25.9 (4.8) | 27.0 (5.5)** |
| Late Stage (IIB, III, IV) | 33% | 32% | 29% | 26% | 35% |
| Tamoxifen | 53% | 52% | 68% | 39% | 58%* |
| Radiation Therapy | 11% | 10% | 15% | 3% | 14%** |
| Social Support Score[3] | 82.0 (22.9) | 83.0 (23.6) | 78.9 (20.1) | 84.2 (24.4) | 81.2 (22.3) |
| Living with a companion | 55% | 58% | 39%* | 72% | 49%*** |
| Hospital Type | | | ** | | * |
|  Government Hospital | 10% | 10% | 8% | 2% | 13% |
|  Non Profit | 80% | 83% | 64% | 11% | 10% |
|  For Profit | 10% | 6% | 28% | 89% | 77% |
| Hospital Teaching Status | | | * | | |
|  No Teaching | 47% | 42% | 61% | 48% | 47% |
|  Low Teaching | 33% | 38% | 14% | 31% | 32% |
|  High Teaching | 21% | 20% | 24% | 20% | 21% |

* p < 0.05, ** p < 0.01, *** p < 0.0

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[2] The Short Form-12 (SF-12) score, developed by the Medical Outcomes Study, is a 12 item, self-administered questionnaire that assesses symptoms, functioning and quality of life. The responses to each question are weighted differently for mental and physical components, and thus generate two scores; a mental and a physical component score. For the general population, the physical and mental SF-12 score have a mean of 50 and standard deviation of 10.

[3] The social support score (0 to 100) was calculated by averaging responses to 8 questions: how often do you have someone to help you if confined to bed, to take you to the doctor if you needed it, to have a good time with, to prepare meals if you are unable, to help with daily chores if sick, to turn to for suggestions or deal with problems, who understands your problems, and to love and make you feel wanted? Individuals can choose from 5 response categories: all of the time (score = 100), most of the time (75), some of the time (50), a little of the time (25), and none of the time (0). (Global Medical Outcomes Study Social Support Scale)

After adjusting for covariates using multivariable analyses (Table 2 below), we found that race/ethnicity effects were no longer significant. However, low-income women were significantly less likely to both discuss and receive reconstruction. Patient age and hospital type were additional significant predictors of reconstruction. Among subset of women with a physician-patient discussion, chest wall radiation, know to be associated with higher rates of reconstruction complications, was an additional significant negative predictor of reconstruction. Although discussion of possible breast reconstruction is considered a measure of breast cancer quality of care, low-income remained a barrier to both discussion and receipt of breast reconstruction. Additionally, three characteristics associated with worse reconstruction outcomes, age, chest wall radiation, and tamoxifen use predicted lower rates of reconstruction. Physician-patient discussion did not eliminate socioeconomic variations in use of reconstruction, but it may allow patients without and with medical contraindications to make appropriate personal choices. While characteristics associated with poor outcome may represent appropriate reasons to discourage use of reconstruction, contraindications did not explain the significantly lower rates of reconstruction observed in low-income women. A manuscript presenting these analyses has been prepared and submitted. [12]

**Table 2: Predicted Probability of Discussion of Breast Reconstruction, Breast Reconstruction, and Breast Reconstruction Among Women with Discussion Based Upon Multivariable Regression[4]**

| | Discussion (n = 391) | Reconstruction (n = 405) | Reconstruction[5] (n = 310) |
|---|---|---|---|
| Age | | | |
| 50_59 [ref][6] | 0.93 [0.86, 1.00] | 0.37 [0.26, 0.49] | 0.51 [0.37, 0.64] |
| 60 to 69 | 0.89 [0.82, 0.96] | 0.170.11, 0.23]*** | 0.24 [0.17, 0.31]*** |
| ≥ 70 | 0.87 [0.78, 0.96] | 0.11 0.05, 0.17]*** | 0.18 [0.08, 0.27]*** |
| Race | | | |
| White [ref] | 0.91 [0.85, 0.96] | 0.24 [0.15, 0.31] | 0.35 [0.25, 0.44] |
| Latino English speaking | 0.95 [0.88, 1.00] | 0.25 0.07, 0.43] | 0.33 [0.11, 0.53] |
| Latino Spanish speaking | 0.83 [0.64, 1.00] | 0.09 [0.00, 0.23] | 0.11 [0.00, 0.27] |
| African American | 0.85 [0.68, 1.00] | 0.13 [0.03, 0.21] | 0.20 [0.05, 0.34] |
| Other | 0.82 [0.64, 0.99] | 0.24 [0.03, 0.51] | 0.45 [0.11, 0.77] |
| Education | | | |
| < High School | 0.89 [0.76, 1.00] | 0.13 [0.02, 0.27] | 0.22 [0.00, 0.46] |
| = High School | 0.91 [0.83, 0.98] | 0.23 [0.13, 0.32] | 0.33 [0.20, 0.45] |
| Some College | 0.94 [0.89, 0.98] | 0.28 [0.17, 0.38] | 0.37 [0.24, 0.49] |
| College Graduate + [ref] | 0.83 [0.73, 0.93] | 0.17 [0.09, 0.24] | 0.28 [0.15, 0.39] |
| Income | | | |
| < 20 K | 0.76 [0.59, 0.92]* | 0.08 [0.01, 0.14]** | 0.14 [0.02, 0.26]* |
| 20 to 40 K | 0.91 [0.82, 1.00] | 0.19 [0.07, 0.31] | 0.30 [0.14, 0.45] |
| > 40 K [ref] | 0.93 [0.88, 0.98] | 0.31 [0.21, 0.40] | 0.39 [0.29, 0.48] |
| Insured [ref] | 0.90 [0.85, 0.94] | Omitted | Omitted |
| Uninsured | 0.92 [0.80, 1.00] | | |
| Employed [ref] | 0.90 [0.80, 0.99] | 0.28 [0.15, 0.40] | 0.40 [0.24, 0.54] |
| Unemployed | 0.90 [0.85, 0.94] | 0.18 [0.13, 0.22] | 0.27 [0.21, 0.33] |
| Physical SF 12 (mean) [ref] | 0.90 [0.85, 0.94] | 0.21 [0.14, 0.26] | 0.31 [0.23, 0.38] |
| Physical SF 12 (mean+SD) | 0.90 [0.84, 0.95] | 0.22 [0.13, 0.29] | 0.31 [0.20, 0.40] |
| Mental SF 12 (mean) | 0.90 [0.85, 0.94] | 0.21 [0.14, 0.26] | 0.31 [0.23, 0.38] |
| Mental SF 12 (mean+SD) | 0.89 [0.83, 0.93] | 0.18 [0.09, 0.27] | 0.27 [0.15, 0.38] |
| Comorbidity Count | | | |

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[4] Presented as predicted probabilities and [95% Confidence Interval].

[5] Receipt of reconstruction among women with physician-patient discussion only.

| | | | |
|---|---|---|---|
| None [ref] | 0.95 [0.89, 1.00] | 0.17 [0.06, 0.27] | 0.28 [0.13, 0.42] |
| 1 to 2 | 0.91 [0.85, 0.96] | 0.26 [0.18, 0.33] | 0.35 [0.25, 0.43] |
| $\geq 3$ | 0.82 [0.70, 0.93] | 0.17 [0.08, 0.24] | 0.29 [0.15, 0.41] |
| Body Mass Index <30 [ref] | 0.90 [0.85, 0.94] | 0.23 [0.14, 0.26] | 0.36 [0.23, 0.38] |
| Body Mass Index $\geq$30 | 0.94 [0.89, 0.97] | 0.16 [0.10, 0.25] | 0.17 [0.14, 0.34]* |
| Early Stage (I, IIA) [ref] | 0.90 [0.85, 0.95] | 0.23 [0.15, 0.30] | 0.34 [0.24, 0.43] |
| Late stage > IIB (I, IIA) | 0.89 [0.82, 0.95] | 0.15 [0.06, 0.23] | 0.25 [0.10, 0.39] |
| Radiation Therapy | 0.90 [0.81, 0.98] | 0.07 [0.00, 0.15] | 0.09 [0.00, 0.19]* |
| No Radiation Therapy [ref] | 0.90 [0.85, 0.94] | 0.23 [0.16, 0.29] | 0.35 [0.26, 0.42] |
| Social Support Score (mean) [ref] | 0.90 [0.85, 0.94] | 0.21 [0.14, 0.26] | 0.31 [0.23, 0.38] |
| Social Support Score (100) | 0.91 [0.86, 0.95] | 0.18 [0.11, 0.25] | 0.28 [0.18, 0.37] |
| Living with companion [ref] | 0.90 [0.85, 0.95] | 0.26 [0.17, 0.33] | 0.38 [0.27, 0.48] |
| Not Living with companion | 0.90 [0.83, 0.96] | 0.15 [0.07, 0.21]* | 0.22 [0.12, 0.31]* |
| Hospital Teaching Status | | | |
| None [ref] | 0.87 [0.80, 0.94] | 0.19 [0.11, 0.25] | 0.09 [0.21, 0.39] |
| Low | 0.94 [0.88, 0.99] | 0.19 [0.09, 0.29] | 0.27 [0.13, 0.40] |
| High Teaching | 0.88 [0.81, 0.94] | 0.29 [0.19, 0.37] | 0.40 [0.27, 0.52] |
| Hospital Type | | | |
| Non-profit [ref] | 0.91 [0.87, 0.95] | 0.22 [0.14, 0.28] | 0.32 [0.23, 0.39] |
| Government | 0.91 [0.78, 1.03] | 0.05 [0.02, 0.06]*** | 0.07 [0.04, 0.10]*** |
| Profit | 0.67 [0.45, 0.88]** | 0.42 [0.04, 0.79] | 0.69 [0.29, 1.09] |

* p < 0.05, ** p < 0.01, *** p< 0.001

We have also analyzed (1) sociodemographic variations in the **discussion of the alternative surgical treatment options** for early stage breast cancer (i.e., breast conserving treatment versus mastectomy) and the **potential risks and benefits of the alternative treatment options**, and (2) the **impact of discussions on patients' satisfaction** with their overall medical care. Using multivariable analyses, we evaluated the impact of physician-patient outcome discussions (i.e., breast cancer recurrence, breast cancer survival, breast appearance, and arm swelling/pain/movement difficulty) on patient satisfaction at baseline and follow-up.

More than half of women reported physician-patient discussions of breast cancer recurrence (54%), breast appearance (50%), and arm pain/swelling/movement difficulty (55%). Less than one third (31%) reported discussing the possible impact of surgery on breast cancer survival.

**Table 3: Self-reported physician-patient discussions of alternative treatments, likely treatment outcomes, and overall satisfaction with medical care**

| | (n = 495) |
|---|---|
| Physician-patient discussion of likely treatment outcomes | % Patients Reporting Discussion |
| Breast cancer recurrence | 54% |
| Survival from breast cancer | 31% |
| Breast or chest wall appearance | 50% |
| Arm swelling, pain, or difficulty with movement after surgery | 55% |
| Mean number of physician-patient treatment outcome discussions (SD)* | 1.9 (1.4) |
| | |
| Overall patient satisfaction with medical care[7] | % Patients Satisfied with Medical Care[8] |
| Satisfied (baseline survey) | 79% |
| Satisfied (follow up survey) | 65% |

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[7] Respondents were asked to rate their overall medical care from 1 (poor) to 10 (best) on the baseline survey and on the follow up survey. We dichotomized the patient satisfaction variable at baseline and follow-up as satisfied (9 and 10) and not satisfied (1 – 8).
[8] Mean number of discussions of a total of four possible discussions

Multivariate analyses revealed two variables that were significantly associated with no physician-patient discussion of alternative treatment options: advanced age (OR 0.4, 95% CI 0.2–0.5 for ages $\geq$ 70 compared to ages 50-59), and less education (OR 0.6, 95% CI 0.4–0.9 for $\leq$ high school compared to college graduates) (Table 4).  Women with high social support scores were more likely to report physician-patient discussions of alternative treatment options.

**Table 4: Predictors of patient-physician discussion of the alternative treatment options and outcomes [9]**

| | Discussion of mastectomy, lumpectomy, and radiation OR (95% CI) (n = 855)[10] | Discussion of any outcome items OR (95% CI) (n = 486)[11] |
|---|---|---|
| Age (50 to 59)[12] | | |
| 60 to 69 | 0.8 (0.5  1.1) | 0.5 (0.3  0.9)* |
| $\geq$ 70 | 0.4 (0.3  0.5)*** | 0.4 (0.2  0.8)** |
| Race (White) [4] | | |
| Latina English-speaking | 1.6 (0.8   3.3) | 1.3 (0.6 2.8) |
| Latina Spanish-speaking | 1.0 (0.6   2.2) | 1.1 (0.5 2.3) |
| African American | 1.1 (0.6   2.3) | 0.7 (0.4 1.3) |
| Other | 1.4 (0.8   2.3) | 0.8 (0.4 1.9) |
| Education (College Grad +)[4] | | |
| High school graduate or less | 0.6 (0.4   0.9)* | 0.4 (0.2 0.7)** |
| Some college | 0.8 (0.5   1.1) | 0.9 (0.5 1.3) |
| Income (> 40 K) [4] | | |
| < 20 K | 0.6 (0.3  1.0) | 1.1 (0.6 1.7) |
| 20 to 40 K | 1.0 (0.7  1.4) | 1.2 (0.7 1.9) |
| Insured (uninsured) [4] | 1.6 (0.7  1.4) | 1.9 (0.7 4.7) |
| Employed (unemployed) [4] | 1.6 (0.7  3.2) | 0.9 (0.6 1.4) |
| Physical SF 12 | 1.0 (1.0  1.1) | 1.0 (1.0 1.0) |
| Mental SF 12 | 1.0 (1.0  1.1) | 1.0 (1.0 1.0) |
| Comorbidity Count (None)[4] | | |
| 1 to 2 | 1.2 (0.8 1.8) | 1.1 (0.7 1.8) |
| $\geq$ 3 | 1.7 (0.8 2.3) | 1.1 (0.6 1.8) |
| Body Mass Index | 1.0 (1.0  1.1) | 1.0 (0.9 1.0) |
| Stage (Stage 2) [4] | | |
| Stage 1 | 0.9 (0.7  1.1) | 1.1 (0.8 1.5) |
| Social Support Score | 1.1 (1.0 1.1)* | 1.0 (1.0 1.0) |
| Living with companion (Not) [4] | 1.3 (0.9 1.9) | 1.4 (1.0 2.0) |

 * p < 0.05, ** p < 0.01, *** p< 0.001

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[9] Multivariable logistic regressions also controlled for hospital characteristics (i.e. financial status, teaching status, and bed size), and clustering within hospitals.
[10] 16 women had missing data for this variable.
[11] The outcome discussions questions were only asked of a random subset of respondents (486 out of 871)
[12] Reference group for the multivariable logistic regression analysis is in parenthesize.

Women who discussed arm swelling/pain/movement difficulty were significantly more likely to be satisfied at baseline (OR 1.8, 95% CI 1.1–3.0, p < 0.05) and follow-up (OR 1.9, 95% CI 1.2–3.0, p < 0.01).  The more treatment outcomes patients discussed with their physicians, the higher patient satisfaction ratings were at baseline and follow-up.  Based on the multivariate model, the percentage of respondents who reported being satisfied with their medical care increases approximately by 4% per count of outcomes discussed both at baseline and follow-up.  In conclusion, we found that rates of physician-patient discussions of alternative treatment options and their potential positive and negative outcomes for breast cancer were relatively low. Rates of physician-patient discussion of outcomes of breast cancer treatment were highly correlated with patients' satisfaction with overall medical care. Women with advanced age and lower education were at higher risk of being excluded from participating in the decision-making process for their breast cancer. This work is presented in a manuscript currently under review. [13]

**Table 5: Impact of Physician-Patient Discussions on Patient Overall Satisfaction with Medical Care**

| | Patient report of satisfaction with care at baseline survey OR (95% CI) (n = 495) | Patient report of satisfaction at follow-up survey OR (95% CI) (n = 495) |
|---|---|---|
| | **Model 1A** | **Model 1B** |
| Physician-patient discussions of likely treatment outcomes | | |
| Breast cancer recurrence (y/n) | 1.5 (0.7 2.9) | 1.0 (0.6 1.6) |
| Survival from breast cancer (y/n) | 1.0 (0.5 2.0) | 0.9 (0.5 1.4) |
| Breast and chest wall appearance (y/n) | 1.1 (0.7 1.7) | 1.0 (0.6 1.4) |
| Arm pain, swelling, or difficulty with movement after surgery (y/n) | 1.8 (1.1 3.0)* | 1.9 (1.2 3.0)** |
| | **Model 2A** | **Model 2B** |
| Count of physician patient discussions (range 0 to 4) | 1.3 (1.1 1.5)*** | 1.3 (0.9 1.3)* |

\* p < 0.05, ** p < 0.01, ** p < 0.001

## PHYSICIAN-LEVEL ANALYSES:

Quality of care is usually conceptualized as being represented by three domains: the structure of care, process of care, and outcomes of care. Analyses are also underway of data on the structure of care for breast cancer patients from a survey of physicians who treated the population-based cohort of breast cancer study patients. We surveyed 477 physicians, targeting all Los Angeles County medical oncologists, radiation oncologists, and surgeons (77% response rate). Survey items were based on the structure and quality of care literature, cognitive interviews with cancer care specialists, and existing physician survey instruments. Data from the physician survey represent important building blocks for further analyses to determine the impact of structural characteristics on the quality of care that breast cancer patients experience. We anticipate that physician-level data may serve as an intermediate level between the neighborhood and individual levels in our multi-level analyses planned for the upcoming final study year.

Analyses of physician and practice demographics thus far indicate that breast cancer care providers in Los Angeles are diverse, with one third non-white and 46% speaking a non-English language. Group practice is most common, (37% single specialty, 16% group-model HMO, 8% multi-specialty group). Minimal teaching involvement predominates. Mean new breast cancer patient volumes, a characteristic associated with better quality breast cancer care, are relatively high (8 per month overall; 6 for surgeons), representing 46% of new cancer patients. Physicians reported high career satisfaction levels (83-92%). The aspect of their practices physicians were least satisfied with was the amount of time spent with patients (82%). This work describing

many of the significant practice characteristics associated with Los Angeles oncologists and surgeons is presented in a manuscript currently under review. [11]

**Table 6a: Demographics: Physician Characteristics, Mean or % (SE)**

| | Medical Oncologist n=111 | Radiation Oncologist n=66 | Surgeon n=171 | All n=348 |
|---|---|---|---|---|
| | | Mean or % (SE) | | |
| Mean Age* | 53.2 (0.8) | 49.5 (1.2) | 53.0 (0.7) | 52.5 (0.5) |
| Gender | | | | |
| % Male | 76.3 (3.9) | 79.4 (4.9) | 86.8 (2.5) | 81.7 (2.1) |
| % Female | 23.7 (3.9) | 20.6 (4.9) | 13.2 (2.5) | 18.3 (2.1) |
| Race/ethnicity | | | | |
| % NH White | 64.0 (4.8) | 65.1 (5.9) | 68.7 (3.6) | 66.4 (2.6) |
| % Asian | 23.0 (4.0) | 24.2 (5.3) | 15.8 (2.8) | 19.8 (2.2) |
| % Other | 7.1 (3.1) | 4.5 (2.6) | 4.7 (1.6) | 5.6 (1.5) |
| % Hispanic (any race) | 2.8 (1.6) | 3.2 (2.2) | 7.8 (2.1) | 5.2 (1.2) |
| % Black | 3.1 (1.7) | 3.1 (2.1) | 2.9 (1.3) | 3.0 (1.2) |
| % with Additional Languages | 46.7 (4.8) | 34.8 (5.9) | 49.0 (3.8) | 45.8 (2.7) |
| Mean Cancer Volume (new patients/month) *** | 28.3 (2.7) | 30.7 (2.0) | 9.8 (0.6) | 20.0 (1.2) |
| Mean Breast Cancer Volume (new patients/ month) *** | 8.9 (0.8) | 12.0 (1.2) | 5.6 (0.5) | 7.8 (0.5) |
| Mean % of cancer patients with breast cancer * | 37.0 (1.9) | 37.7 (2.5) | 54.8 (1.8) | 45.5 (1.3) |
| Mean number of offices for seeing patients *** | 1.7 (0.1) | 2.5 (0.3) | 1.4 (0.1) | 1.7 (0.1) |
| Respondent ownership interest in practice ∞ | | | | |
| Full owner | 32.4 (4.6) | 20.0 (5.0) | 52.1 (3.8) | 39.6 (2.7) |
| Part owner | 42.9 (4.8) | 37.9 (6.0) | 30.8 (3.5) | 36.4 (2.6) |
| No ownership interest | 24.7 (4.1) | 42.1 (6.1) | 17.2 (2.9) | 24.0 (2.3) |

* Lincom comparison of means, P < 0.05
** Lincom comparison of means, P < 0.01
*** Lincom comparison of means, P < 0.001
∞ Chi Square, P<0.001

**Table 6b: Demographics: Practice Characteristics, % (SE)**

| | Medical Oncologist n=111 | Radiation Oncologist n=66 | Surgeon n=171 | All n=348 |
|---|---|---|---|---|
| | | | % (SE) | |
| **Practice type *** | | | | |
| Single-specialty group | 43.8 (4.8) | 60.9 (6.0) | 23.9 (3.2) | 37.2 (2.6) |
| Solo | 25.5 (4.3) | 7.7 (3.3) | 43.1 (3.8) | 30.9 (2.5) |
| Group model HMO | 15.0 (3.7) | 11.9 (4.0) | 17.2 (2.8) | 15.5 (2.0) |
| Multi-specialty group | 4.5 (2.0) | 10.5 (3.8) | 9.5 (2.3) | 7.8 (1.4) |
| University-based | 9.6 (2.8) | 9.1 (3.5) | 5.2 (1.7) | 7.5 (1.4) |
| Other | 1.6 (1.2) | 0 (0.0) | 1.1 (0.8) | 1.1 (0.6) |
| **Practice best described as *** | | | | |
| Office-based | 91.5 (2.6) | 61.9 (6.0) | 57.2 (3.8) | 70.6 (2.4) |
| Hospital-based | 6.7 (2.3) | 33.7 (5.8) | 31.9 (3.6) | 22.9 (2.2) |
| Both | 1.8 (1.3) | 3.0 (2.1) | 7.9 (2.0) | 4.9 (1.1) |
| Other | 0 (0.0) | 1.5 (1.5) | 3.0 (1.3) | 1.7 (0.7) |
| **Practice ownership *** | | | | |
| One or more physicians, or a physician-owned corporation | 74.5 (4.4) | 56.2 (6.1) | 73.1 (3.4) | 70.9 (2.5) |
| HMO, health plan, or insurance company | 14.3 (3.7) | 13.4 (4.2) | 18.0 (2.9) | 15.9 (2.0) |
| Hospital | 0.9 (0.9) | 16.7 (4.6) | 4.0 (1.5) | 4.9 (1.1) |
| Medical school/university | 6.2 (2.3) | 6.0 (2.9) | 1.8 (1.0) | 4.1 (1.1) |
| County government | 3.4 (1.7) | 1.6 (1.6) | 1.2 (0.8) | 2.1 (0.8) |
| Some other type of owner | 0.9 (0.9) | 4.7 (2.7) | 1.9 (1.1) | 2.0 (0.7) |
| Don't know | 0 (0.0) | 1.5 (1.4) | 0 (0.0) | 0.2 (0.2) |
| **Practice Size** | | | | |
| 1 | 22.4 (4.1) | 7.8 (3.3) | 37.6 (3.7) | 27.2 (2.5) |
| 2-5 | 43.3 (4.8) | 47.2 (6.2) | 24.4 (3.3) | 35.0 (2.6) |
| 6-15 | 18.7 (3.6) | 19.8 (4.9) | 10.1 (2.3) | 14.8 (1.9) |
| 16-49 | 0.9 (0.9) | 20.8 (5.0) | 4.1 (1.5) | 5.6 (1.2) |
| 50-99 | 1.6 (1.1) | 0 (0.0) | 2.9 (1.3) | 2.0 (0.7) |
| 100+ | 13.2 (3.6) | 4.5 (2.5) | 21.0 (3.1) | 15.5 (2.0) |

* Chi Square, P < 0.05
** Chi Square, P < 0.01
*** Chi Square, P < 0.001

**Table 7: Physician Satisfaction: % Reporting Very or Somewhat Satisfied (Standard Error)**

| | Medical Oncologist n=111 | Radiation Oncologist n=66 | Surgeon n=171 | All n=348 |
|---|---|---|---|---|
| | | % (SE) | | |
| Satisfaction with the following areas of medical practice: | | | | |
| Your current practice specialty | 91.8 (2.6) | 93.8 (3.0) | 91.2 (2.2) | 91.8 (1.5) |
| Your decision to become a physician | 91.5 (2.6) | 92.3 (3.3) | 88.2 (2.5) | 90.1 (1.6) |
| Your current work setting | 90.3 (2.8) | 86.1 (4.3) | 88.9 (2.4) | 89.0 (1.7) |
| Your overall professional career | 89.6 (2.9) | 92.4 (3.3) | 87.1 (2.6) | 88.9 (1.7) |
| Extent to which this practice has met your professional expectations | 88.5 (3.0) | 89.1 (3.9) | 85.4 (2.7) | 87.1 (1.8) |
| The amount of time you can spend with a patient | 79.6 (3.8) | 89.4 (3.8) | 80.3 (3.0) | 81.5 (2.1) |

We also examined **physician reports of the financial incentives** they face (Table 8). Physicians were asked whether they were subject to explicit incentives for quality (i.e., receipt of additional income for scoring well on (a) patient satisfaction surveys or (b) other measures of quality such as guideline adherence) within 12 months prior to the survey. We examined the prevalence, correlates and predictors of such incentives. Covariates included practice characteristics (managed care involvement, practice type, size), and physician characteristics (age, specialty, ownership interest, volume). Descriptive analyses were performed including comparisons of categorical variables using Chi-squares.   We performed multivariable logistic regression analyses to predict use of explicit incentives controlling for other covariates, weighted for non-response and clustering of physicians within office.  Overall, 23% of respondents reported being subject to explicit incentives for quality. Bivariate results indicate that physicians' reported use of explicit incentives for quality in their main practices varied significantly by level of managed care involvement, practice type, size, and physician ownership interest. In bivariate analysis, use of explicit incentives for quality increased monotonically with level of managed care involvement, and physicians from the largest practice types reported the highest prevalence of explicit incentive use, likely due to confounding with group-model HMO practice type. In multivariable analyses, group model HMO practice type was more likely to be associated with reported use of incentives for quality as compared with solo practice type, controlling for physician age, gender, breast cancer volume, ownership interest, reimbursement type, and practice size and type (p<0.0001)(Table 10). Physician age, gender, volume, and specialty type were not significantly associated with use of explicit incentives for quality. Among non-HMO breast cancer care providers only, significant predictors of explicit incentives for quality were ownership interest and reimbursement in the form of capitation, controlling for practice type, specialty type, practice size and percentage of reimbursements in the form of fee-for-service payments. Use of explicit incentives for quality among breast cancer providers in Los Angeles County was reported at modest rates, and was primarily associated with a high level of managed care involvement: affiliation with a group-model HMO or managed care arrangements involving capitated payments. Its use was less common amongst providers with full practice ownership interest and those with less managed care involvement.

**Table 8: Physician Financial Reimbursement Characteristics by Specialty Type, Mean or %, (SE) (Weighted for Survey Non-response)**

| | Medical Oncologist n=111 | Radiation Oncologist n=66 | Surgeon n=171 | All n=348 |
|---|---|---|---|---|
| | **Mean (S.E.)** | | | |
| Mean Percentage of physician personal reimbursement paid in the form of: | | | | |
| | **Mean Percent (S.E.)** | | | |
| Salary, fixed | 45.2 (5.9) | 45.3 (9.7) | 30.6 (5.4) | 38.4 (3.7) |
| Salary that may vary (e.g., based on productivity) | 6.7 (2.0) | 12.8 (3.8) | 5.9 (1.5) | 7.3 (1.2) |
| Fee-for-Service | 37.3 (5.3) | 30.0 (7.0) | 53.9 (5.0) | 43.9 (3.3) |
| Capitation | 7.3 (2.0) | 5.5 (2.6) | 4.8 (1.2) | 5.8 (1.0) |
| Percentage of physician respondents paid… | | | | |
| | **Percent (S.E.)** | | | |
| Predominantly (>50%) in the form of salary | 50.2 (6.1) | 57.1 (9.3) | 35.9 (5.6) | 44.6 (3.9) |
| Predominantly (>50%) in the form of Fee-For-Service | 38.2 (5.7) | 29.2 (7.3) | 53.4 (5.2) | 43.9 (3.5) |
| A*ny* amount of capitated payments | 20.1 (3.9) | 16.1 (4.7) | 14.8 (2.8) | 17.0 (2.1) |
| Percentage of physicians by level of managed care involvement (based on patient case mix) | | | | |
| | **Percent (S.E.)** | | | |
| Network model, <50% mg'd care pts* | 43.6 (4.8) | 47.6 (6.3) | 43.7 (3.9) | 44.3 (2.7) |
| Network model, >50% mg'd care pts* | 42.1 (4.8) | 40.0 (6.2) | 38.7 (3.8) | 40.2 (2.7) |
| Group model HMO | 14.3 (3.7) | 12.5 (4.1) | 17.6 (2.9) | 15.5 (2.0) |

- may include Medicare, Medicaid, or commercial managed care
* Lincom comparison of means, $P < 0.05$
** Lincom comparison of means, $P < 0.01$
*** Lincom comparison of means, $P < 0.001$
∞ Chi Square, $P<0.001$

**Table 9: Explicit Financial Incentives: "In the last 12 months, was your pay affected in any way by the following (e.g., were you eligible for a bonus or other incentive?"**

| | Medical Oncologist n=111 | Radiation Oncologist n=66 | Surgeon n=171 |
|---|---|---|---|
| | **% Answering Yes** | | |
| Results of satisfaction surveys | 26 | 16 | 15 |
| Quality of care measures | 17 | 13 | 12 |

**Table 10: Predicted Probability\* of Use of Any Explicit Financial Incentives, N=348**

| | Predicted Probability |
|---|---|
| **Practice Type\*\*** | |
| Group Model HMO | 70 |
| Solo Practice | 16 |
| Multi-Specialty Medical Group | 12 |
| University/County | 11 |
| Single-Specialty Medical Group | 10 |

\* Predicted Probabilities based on multivariable logistic regression controlling for MD specialty type, ownership interest in practice, practice size, % FFS reimbursements
\*\* P < 0.01

We also examined how physicians perceived their overall, **individual financial incentives** with respect to selected clinical practices and services pertinent to breast cancer care (n=8 items for medical oncologists, 6 for radiation oncologists, 3 for surgeons). For example, medical oncologists were asked to describe their individual financial incentives regarding the use of office-based parenteral chemotherapy. Respondents were asked to indicate whether on balance, incentives favor reducing the practice or service, expanding it, or neither. We examined the prevalence of self-reported incentives to reduce or expand each practice or service. Descriptive analyses were weighted for physician survey non-response. Self-reports of implicit financial incentives to reduce or expand practices or services varied by specialty type and item. For example, among medical oncologists, rates of incentives either to reduce or expand practices or services ranged from 42% for office-based chemotherapy to 16% for use of in-dwelling venous catheter. Among radiation oncologists, rates ranged from 21% for CT-based treatment planning to 14% for stereotactic radiosurgery. Among surgeons, rates ranged from 11% for hospitalization to 6% for patient enrollment in clinical trials. Among medical oncologists who reported any incentives, incentives to expand services were reported for 4 out of 8 items (e.g., office-based chemotherapy) and incentives to reduce services were reported for 2 of 8 items (e.g., referral to other cancer care providers). Among radiation oncologists who reported any incentives, 4 of 6 services examined were associated with incentives to expand services. Among surgeons who reported any incentives, incentives were equally likely to be associated with service reduction (e.g., hospitalization) as with more service use (e.g., clinical trial enrollment). The majority of physicians delivering specific cancer treatments in Los Angeles County reported perceiving no overall personal financial incentives to reduce or expand the practices or services studied. However, across the nine services studies, notable proportions of physicians did report financial incentives either to reduce or expand performance. Of these items, incentives were more often reported to favor expanding the practice or service. Most prevalent reports of incentives to expand services were among medical oncologists with respect to office-based chemotherapy and growth factor injections. With respect to clinical trial enrollment, reports of incentives to expand services were most prevalent across all three specialty types, but most frequently among medical oncologists.

This work addressing financial incentives has been presented in abstract form [14, 15], and is being prepared as a manuscript for submission to *The Journal of Clinical Oncology*.

**Table 11a-d: Physician Self-reported, Perceived Financial Incentives: Selected Items by Specialty Type (Weighted for Survey Non-response)**

a. Medical Oncologists Only: How would you describe your overall personal incentives regarding the following practices or services? On balance, do these incentives favor reducing this practice or service, expanding this practice or service, or neither?

| | Neither | Reducing | Expanding |
|---|---|---|---|
| | % (SE) | | |
| Use of parenteral chemotherapy in office | 56.9 (5.9) | 11.7 (3.4) | 30.5 (5.4) |
| Use of growth factor injections in office | 58.1 (5.9) | 8.9 (3.0) | 31.2 (5.3) |
| Use of parenteral chemotherapy in hospital | 63.0 (5.1) | 23.2 (4.2) | 12.0 (3.3) |
| Use of growth factor injections, home | 71.8 (4.5) | 12.0 (3.2) | 13.3 (3.2) |
| Hospitalization for Medical Conditions | 75.7 (4.7) | 11.1 (3.0) | 10.4 (3.0) |
| Referral to other cancer care providers | 80.0 (4.0) | 15.4 (3.5) | 3.6 (1.8) |
| Use of PICC line or indwelling catheter | 80.3 (4.4) | 2.9 (1.6) | 13.8 (3.4) |

b. Radiation Oncologists Only: How would you describe your overall personal incentives regarding the following practices or services? On balance, do these incentives favor reducing this practice or service, expanding this practice or service, or neither?

| | Neither | Reducing | Expanding |
|---|---|---|---|
| | % (SE) | | |
| Use of IMRT | 73.9 (6.4) | 1.5 (1.5) | 18.3 (5.5) |
| Stereotactic radiosurgery | 74.1 (6.8) | 1.5 (1.5) | 12.1 (4.0) |
| CT-based treatment-planning (b) | 77.1 (6.5) | 1.5 (1.5) | 19.9 (5.0) |
| Use of brachytherapy | 83.0 (5.1) | 4.6 (2.6) | 10.9 (4.2) |
| Use of greater number of fractions? | 84.7 (5.3) | 4.6 (3.4) | 9.2 (3.7) |

c. Surgeons Only: How would you describe your overall personal incentives regarding the following practices or services? On balance, do these incentives favor reducing this practice or service, expanding this practice or service, or neither?

| | Neither | Reducing | Expanding |
|---|---|---|---|
| | % (SE) | | |
| Hospitalization for medical conditions | 78.6 (3.5) | 7.3 (2.0) | 4.1 (1.5) |
| Referral of patients to other cancer care providers | 80.9 (3.3) | 4.9 (1.7) | 4.2 (1.5) |

Note: %'s reporting "don't know" not shown

d. All specialty types: How would you describe your overall personal incentives regarding …**patient enrollment in clinical trials**? On balance, do these incentives favor reducing this practice or service, expanding this practice or service, or neither?

| | Neither | Reducing | Expanding |
|---|---|---|---|
| | % (SE) | | |
| Med Onc | 67.8 (4.9) | 5.6 (2.3) | 22.8 (4.7) |
| Surgeon | 82.2 (3.4) | 1.9 (1.1) | 4.1 (1.7) |
| Rad Onc | 86.3 (4.9) | 1.5 (1.5) | 7.5 (3.2) |
| All | 77.5 (1.5) | 3.2 (1.0) | 11.6 (2.1) |

Note: %'s reporting "don't know" not shown

Another priority topic under study at the physician level is the **use of interpreter services** among physicians with Limited English-Proficient (LEP) patients. These data will be important in our linkages between quality of care for Hispanic women, characteristics of providers seen by these women, and characteristics of neighborhoods in which these women reside. We queried study physicians about the proportion of LEP patients seen in their main practice, the type and frequency of interpreter use, and the impact on physician satisfaction with time spent with patients. On average, Los Angeles County physicians who treated breast cancer patients in our study cohort reported that 17% of their patients were LEP, with Spanish the most prevalent language (88%). Physicians most often reported using bilingual staff (76%) or patient's friends and family members as interpreters (86%)(Table 12). Physician race/ethnicity and practice setting were significant predictors of the proportion of LEP patients. Physician race/ethnicity, specialty and practice setting were significant predictors of the type of interpreter use. Physician age, specialty, practice setting and size were significant predictors of the availability of interpreters to physicians when physicians needed them. Higher proportions of LEP patients were associated with decreased reports of physician satisfaction in time spent with patients, while greater availability of interpreters was associated with increased satisfaction (Table 13).

**Table 12: Physician and Practice Setting Characteristics Identified by Physician Respondents (N=347)[1,2],**

| Variable | All<br><br>N=347 | Medical Oncologist<br>N=111 | Radiation Oncologist<br>N=65 | Surgeon<br><br>N=171 |
|---|---|---|---|---|
| Proportion of LEP patients[3] | 17%<br>(5%, 20%) | 16%<br>(5%, 20%) | 18%<br>(10%, 20%) | 18%<br>(5%, 25%) |
| Interpreter Use by Physician | | | | |
| Physician Acts as Interpreter | 39% | 38% | 30% | 44% |
| Trained Medical Interpreter | 41% | 40% | 51% | 40% |
| Telephone Language Interpretation Services | 21% | 16% | 37% | 19% |
| Bilingual Office Staff | 76% | 77% | 91% | 69% |
| Patient's Friends or Family | 86% | 85% | 89% | 85% |
| Availability of Interpreter Services: Never or Rarely Available When Needed | | | | |
| Trained Medical Interpreter | 55% | 57% | 34% | 61% |
| Telephone Language Interpretation Services | 58% | 63% | 31% | 63% |
| Bilingual Office Staff | 6% | 6% | 0% | 8% |
| Patient's Friends or Family | 2% | 1% | 0% | 4% |
| Mean Interpreter Use Scores[3*] | 195<br>(150, 225) | 189<br>(150, 225) | 208<br>(200, 225) | 195<br>(150, 225) |
| Physician Satisfaction | | | | |
| Satisfied with amount of time spent with patient | 81% | 80% | 89% | 80% |

[1]Weighted for non-response, controlling for physician clustering at office address level
[3]25th percentile and 75th percentile in parentheses
* p<0.05

**Table 13: Multivariate Logistic Regression Predicting Physician Report of Satisfaction with Time Spent with Patients[1]**

| | **Physician satisfaction: Time spent with patient** | | |
|---|---|---|---|
| | Model 1[2]<br>Odds ratios<br>p-values | Model 2[2]<br>Odds ratios<br>p-values | Model 3[2]<br>Odds ratios<br>p-values |
| Proportion of LEP patients | **0.979**<br>**0.002** | | **0.979**<br>**0.003** |
| Intensity of Interpreter Use Score | | **1.005**<br>**0.030** | **1.007**<br>**0.020** |

[1]: The results were weighted for non-response, controlling for physician clustering at office address level
[2]: We also controlled for physician age, gender, race/ethnicity, specialty, practice setting and large practice size. We found no statistically significant differences with the following exceptions: Non-Hispanic Blacks physicians (n=10) were less likely to report

being very or somewhat satisfied with time spent with patients (p<0.01) compared to Non-Hispanic White physicians in all models.  In Model 2, radiation oncologists were more likely to report being satisfied with time spent with patients compared to medical oncologists.

As reported in 2006, we have developed a score for the quality of **physician symptom evaluation**. Preliminary results were presented in abstract form  [17]. We have found that the symptom evaluation score varies with cancer care provider specialty type (with medical oncologists scoring highest, surgeons lowest), and with symptom. In multivariate analyses, an observed female gender effect disappeared when we controlled for visit duration, indicating that female physicians spend more time with their breast cancer patients as compared with male physicians. Other structural factors supporting symptom evaluation appeared to be higher breast cancer volume and single-specialty group practice. A manuscript reporting findings is under preparation.

**Table 14: Mean % of Best Possible Symptom Evaluation Score, by Specialty Type**

|  | Mean % (95% Confidence Interval) |
|---|---|
| Med Onc | 73 (68 - 78) |
| Rad Onc | 61 (54 – 68) |
| Surgeon | 34 (31 - 37) |
| Overall | 52 (49 – 56) |

**Table 15: Significant Predictors of Higher Symptom Evaluation Score: Multivariate OLS Results**

| Physician and Practice Characteristics | Coefficient (SD) | P-Value |
|---|---|---|
| Visit Duration | 0.01 (0.002) | 0.002 |
| Specialty Type |  |  |
| Radiation Oncologist | -0.13 (0.06) | 0.04 |
| Surgeon | -0.25 (0.04) | 0.000 |
| Practice Type |  |  |
| Single-specialty grp | 0.09 (0.04) | 0.007 |
| Multi-specialty grp | 0.02 (0.06) | 0.78 |
| University-based | 0.01 (0.07) | 0.93 |
| Staff/Grp HMO | -0.07 (0.07) | 0.33 |
| Other | -0.18 (0.13) | 0.17 |
| Felt Responsibility | 0.16 (0.06) | 0.007 |

Reference groups: medical oncologist, solo practice type;
Controlling for age, gender, practice size, BC volume, volume x specialty interaction

Next steps will involve linking patient and provider reports of symptom management and controlling simultaneously for *patient* and *physician* predictors of patients receiving the help they wanted with symptoms. A special challenge will involve addressing issues of selection effects and choice of appropriate analytic methods (e.g., propensity score, instrumental variables methods) to do so.

Training and Mentoring Activities:

Throughout the study period to date, Dr. Tisnado has taken advantage of opportunities to obtain additional education in geographic analysis, neighborhood-level measures of socio-economic standing and social capital, and hierarchical modeling methodologies to appropriately represent the data structure of patients nested within physicians offices and within neighborhoods. As part of her training and mentoring plan, Dr. Tisnado has attended special methods seminars offered through UCLA's statistical support center and through the Academy Health Association's seminars in health services research methods. In addition, she attends a journal club for junior investigators engaged in research involving hierarchical modeling methods and neighborhood-level effects on health, as well as weekly meetings with her primary mentor and regularly scheduled mentoring sessions with senior colleagues and peers at least monthly.

## KEY RESEARCH ACCOMPLISHMENTS

- In census tract-level analyses, each of three different definitions of "Hispanic neighborhood" or enclave was associated with numerous census tract-level measures of socio-economic resources and of acculturation.

- In patient-level analyses, we have found evidence of the persistence of racial/ethnic and socio-economic disparities in the health care system with respect to certain aspects of breast cancer treatment such as symptom management [9, 10] and communication about and receipt of different treatment options [12, 13]. Better communication is associated with higher patient satisfaction [13].

- In provider-level analyses, we have described several aspects of the structural landscape in which oncologists and surgeons treating breast cancer in Los Angeles practice. The following findings are reported in a manuscript currently under review at *The Breast Journal*. [11]
    - o Volumes of new breast cancer patients, a characteristic associated with better quality breast cancer care, are high. Breast cancer represents 46% of all new cancer patients seen by study oncologists and surgeons.
    - o Physicians treating breast cancer patients reported high career satisfaction levels. Physicians were least satisfied with the amount of time spent with patients.

- We have analyzed physician reports of the financial incentives they face. We are currently preparing manuscripts reporting the following findings. [14, 15]
    - o Use of explicit financial incentives tied to performance on quality of care measures was reported at modest rates, and was primarily associated with a high level of managed care involvement.
    - o The majority of physicians delivering breast cancer treatments in Los Angeles County reported perceiving no overall personal financial incentives to reduce or expand the services studied. Most prevalent reports of incentives to expand services were among medical oncologists with respect to office-based chemotherapy and growth factor injections and, to a lesser extent, clinical trial enrollment.

- Physicians most often reported using patient's friends and family members as interpreters, as compared with trained medical interpreters. Higher proportions of limited-English proficient patients were associated with decreased physician satisfaction with time spent with patients, but greater intensity of

interpreter service use was associated with higher satisfaction. A manuscript reporting these findings has been submitted to the journal *Medical Care.* [16]


## 2006-2007 REPORTABLE OUTCOMES

Published Journal Articles:

- Yoon J, Malin J, Tao, ML, **Tisnado DM**, Adams JA, Timmer M, Ganz PA, Kahn KL. Symptoms after breast cancer treatment: are they influenced by patient characteristics? *Breast Cancer Research and Treatment*. 2007 May 10 [E-pub ahead of print].

- Yoon J, Malin J, **Tisnado DM**, Tao, ML, Adams JA, Timmer M, Ganz PA, Kahn KL. Symptom management after breast cancer treatment: is it influenced by patient characteristics? *Breast Cancer Research and Treatment*. *Breast Cancer Research and Treatment*. 2007 Jul 19; [Epub ahead of print].

Abstracts/Poster Presentations:

- **Tisnado DM**, Misra A, Malin J, Tao M, Ganz P, Kahn KL. Measuring Symptom Evaluation for Breast Cancer Patients and Associations with Provider and Practice Characteristics. National Institute of Aging Resource Centers for Minority Aging Research Annual Conference, February, 2007

- Rose Ash D, **Tisnado DM**, Malin J, Tao ML, Ganz P, Kahn KL. "Physician practice styles and referral patterns: a model from breast cancer care, Los Angeles Women's Health Study. Society of General Internal Medicine 30th Annual Meeting, April 25-28, 2007.

- Rose Ash D, **Tisnado DM**, Malin J, Tao ML, Ganz P, Kahn KL. "Physician use of health professionals and support staff in caring for a population-based cohort: Results from the Los Angeles Women's (LAW) Study. Society of General Internal Medicine 30th Annual Meeting, April 25-28, 2007.

- **Tisnado DM**, Rose Ash D, Malin J, Tao ML, Ganz P, Hu A, Adams J, Kahn KL. "Explicit incentives for quality in breast cancer care: Physician reports from the Los Angeles Women's Health Study" Academy Health Annual Research Meeting, June 4, 2007.

- **Tisnado DM**, Rose Ash D, Malin J, Tao ML, Ganz P, Hu A, Adams J, Kahn KL. Physician self-reported financial incentives in breast cancer care: Results from the Los Angeles Women's Health Study. Academy Health Annual Research Meeting, June 4, 2007.

- Rose-Ash D, **Tisnado DM**, Malin J, Ganz PA, Tao M, Hu A, Maggard M, Kahn KL. Use of Interpreters by Physicians Treating Women with Breast Cancer: Results from the Los Angeles Women's Health Study. Academy Health Annual Research Meeting, June 4, 2007.

- **Tisnado DM**, Malin J, Ganz P, Tao M, Hu A, Adams J, Kahn KL. Breast Cancer Patient Race/Ethnicity, Neighborhood, and Hospital Quality: Are They Related? Resource Centers for Minority Aging Community Advisory Board Meeting and Investigator Retreat, June 18, 2007.

Applications for Future Funding:

- The work supported by the DOD training grant provided the foundation for a pilot study funded by the National Institute of Aging through the UCLA Resource Center for Minority Aging Research (RCMAR) based on segmented assimilation theory, [6, 8, 19] to examine immigrant neighborhoods and the effects

they may confer on the quality of breast cancer care for Latina patients residing in more disadvantaged and less disadvantaged immigrant neighborhoods as compared with non-immigrant neighborhoods.

- The work supported by the DOD training grant will form the foundation for an NCI-funded career transition award application to specifically explore the effects that *immigrant* neighborhoods may confer on health outcomes for Latino/a and Chinese cancer patients residing in more disadvantaged and less disadvantaged immigrant neighborhoods as compared with non-immigrant neighborhoods in Northern and Southern California.

- Dr. Tisnado has also been nominated for a junior investigator award from the UCLA Jonsson Comprehensive Cancer Center.

**CONCLUSIONS:**

Plans are currently underway for the linkage of the patient, neighborhood and physician data taking into account the appropriate data structure of patients nested within physician and also within neighborhood, necessary for the multi-level multivariate modeling approach. [18] Delays in the completion of this process and in the creation of the linked data set were due to delays in LAWHS project in finalizing the outcome variables (explicit quality of care scores and scores of patient ratings of physicians), stemming in part from the departure of the co-investigator and a key study programmer for employment in the private sector. However, in light of these challenges, steps were taken to conserve funds for an additional year of work during which tasks originally planned for Year 3 would be completed. This additional no-cost extension year was approved on June 11, 2007.

In summary, work has progressed well, and the majority of the Year 1 and 2 tasks have been completed. Remaining to be completed are: 1) Linkage of the patient survey, physician, and neighborhood-level data sets; 2) Calculation of distance from patients to health care providers; 3) Multi-level, multivariate analyses to examine the key study hypotheses; and 4) Manuscript writing pertinent to results of multi-level analyses of the impact of neighborhood, physician, and patient-level factors on quality of breast cancer care.

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10. Yoon J, Malin J, **Tisnado DM**, Tao, ML, Adams JA, Timmer M, Ganz PA, Kahn KL. Symptom management after breast cancer treatment: is it influenced by patient characteristics? *Breast Cancer Research and Treatment*. *Breast Cancer Research and Treatment*. 2007 Jul 19; [Epub ahead of print].

11. **Tisnado DM**, Malin J, Tao M, Ganz PA, Rose-Ash D, Hu A, Adams JA, Kahn KL. "The Structural Landscape of the Health Care System for Breast Cancer Care in Los Angeles County:  Results from a Physician Survey." Unpublished manuscript: Submitted and under review at *The Breast Journal.*

12. Chen J, **Tisnado DM**, Ganz PA, Tao, ML, Malin J, Timmer M, Adams JA, Ko C, Kahn KL "Who receives breast reconstruction post-mastectomy?" Unpublished manuscript: Submitted and under review at *Cancer.*

13. Chen J, **Tisnado DM**, Ganz PA, Tao, ML, Malin J, Timmer M, Kahn KL. "Who is at risk for being excluded from the decision making process for breast cancer treatment?" Unpublished manuscript: Submitted and under review at *Medical Care.*

14. **Tisnado DM**, Rose Ash D, Malin J, Tao ML, Ganz P, Hu A, Adams J, Kahn KL.  "Explicit incentives for quality in breast cancer care: Physician reports from the Los Angeles Women's Health Study" Academy Health Annual Research Meeting, June 4, 2007.

15. **Tisnado DM**, Rose Ash D, Malin J, Tao ML, Ganz P, Hu A, Adams J, Kahn KL.  Physician self-reported financial incentives in breast cancer care: Results from the Los Angeles Women's Health Study. Academy Health Annual Research Meeting, June 4, 2007.

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17. **Tisnado DM**, Misra A, Malin J, Tao M, Ganz P, Kahn KL. Measuring Symptom Evaluation for Breast Cancer Patients and Associations with Provider and Practice Characteristics. National Institute of Aging Resource Centers for Minority Aging Research Annual Conference, February, 2007

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**APPENDIX I:**

The majority of the Year 1 and 2 tasks have been completed. Remaining to be completed are: 1) Linkage of the patient survey, physician, and neighborhood-level data sets; 2) Calculation of distance from patients to health care providers; 3) Multi-level, multivariate analyses to examine the key study hypotheses; and 4) Manuscript writing.

**To address Specific Aim 4 tasks originally planned for Year 3**: Year 3 tasks to address Specific Aim 4 deal primarily with executing the multivariate, multi-level analyses for testing Study Hypotheses 4 and 5, regarding the relative importance of ethnicity, language, and socioeconomic position and how they relate to the structural characteristics of settings in which women receive care, the care women do and do not receive, and, ultimately, to patient quality of care for the population-based sample of Hispanic Spanish-speaking, Hispanic English-speaking, and non-Hispanic white women with breast cancer. We intend pursue testing of these key hypotheses described in the original proposal during this final study year.

In addition, as part of her proposed mentored career development activities, Dr. Tisnado is developing a career development award proposal, which builds on DOD-funded work to examine neighborhood-level effects of predominantly immigrant neighborhoods on cancer care in a national cancer patient cohort. This proposal is to be submitted to the National Cancer Institute for the October 2007 Cycle.

Tasks for the final year will take place according to the following revised Statement of Work:

**WORK PLAN**

| Time period | Tasks | Milestone | % Effort |
|---|---|---|---|
| | **Research Project** | | |
| **On-going** | Weekly project meetings with mentor, Katherine Kahn, and statistical consultants | | 5% ongoing |
| **Q.1** | | | |
| June-July, 2007 | Complete manuscripts regarding MD financial incentives, interpreter services, and neighborhood effects on survey response | Manuscripts submitted | 35 |
| June-July, 2007 | Merge patient survey and physician data together with the already created file containing patient registry and neighborhood data | Finalize analytic data set | 35 |
| July-Aug, 2007 | Calculate measure of distance from patients to providers, merge into dataset | | 35 |

| | | | |
|---|---|---|---|
| July-Aug, 2007 | Begin descriptive bivariate statistics among neighborhood and person-level variables for the overall cohort and for subsets of Hispanic Spanish-speaking, Hispanic English-speaking, and non-Hispanic white patients. | Begin descriptive and bivariate analyses to inform multivariate model development, as well as analyses to examine Hypothesis 3, that Hispanic women will reside in communities of lower SEP that are more isolated from health services, particularly those pertinent to breast cancer diagnosis and treatment. | 35 |
| **Q.2** | | | |
| Sept-Oct, 2007 | Continue bivariate analyses among neighborhood and person-level variables for the overall cohort and for subsets of Hispanic Spanish-speaking, Hispanic English-speaking, and non-Hispanic white patients. | Complete bivariate analyses and examination of Hypothesis 3. | 35 |
| Oct-Nov, 2007 | Develop multivariate modeling approach in Stata. Begin analyses for hypothesis testing. | Begin multi-level modeling analyses to examine questions associated with Hypotheses 4 and 5 | 35 |
| **Q.3** | | | |
| Dec-Feb, 2007 | Continue analyses with multi-level modeling approach. Explore endogeneity problems and analytic options. | Develop and implement final full models addressing research questions associated with Study Hypotheses 4 and 5, catalogue findings | 35 |

| Q.4 | | | |
|---|---|---|---|
| Mar-May, 2007 | Manuscript writing addressing research questions associated with Study Hypotheses 4 and 5:<br>1. Does lower socio-economic position as measured by individual and neighborhood-level factors predict poorer quality of breast cancer care? Is greater variation in quality of care explained by the addition of neighborhood level factors as compared with using individual factors alone? What is the relative importance of patient, provider, and neighborhood characteristics in explaining variation in explicit process of care (quality of care)?<br>2. Are disparities in quality associated with Hispanic ethnicity and Spanish-speaking explained by independent effects of both individual and neighborhood-level indicators of socioeconomic position?<br>3. How much variation is explained by within versus between-physician office and within versus between neighborhood effects? | Complete and submit manuscripts addressing research questions associated with Study Hypotheses 4 and 5: | |

**OTHER POSTDOCTORAL AWARD-RELATED ACTIVITIES**

| Time period | Tasks | Milestone | % Effort |
|---|---|---|---|
| | **Mentoring/Training** | | |
| On-going | Career meetings with mentor, Katherine Kahn | | 2% ongoing (donated time) |
| | Bi-monthly meetings with neighborhood-level analysis study group led by neighborhoods and health researcher Dr. Ninez Ponce | | 2% ongoing, (donated time) |

| | Monthly meetings with other mentors and neighborhoods and health experts from UCLA and RAND | | 1% ongoing, (donated time) |
|---|---|---|---|
| June 2007 | Seminar on Hierarchical Linear Modeling | Seminar completed | 2% for June, 2007, (donated time) |
| | **Grant Writing** | | |
| June-Sept 2007 | Development of proposal to build on DOD-funded work to examine neighborhood-level effects of predominantly immigrant neighborhoods on cancer care in a national cancer patient cohort | Submission of Nation Cancer Institute K-22 (Career Development/ Transition Award) Application | 10% for June-Sept (donated time) |

# APPENDIX II:

## PUBLISHED MANUSCRIPTS

# Symptoms after breast cancer treatment: are they influenced by patient characteristics?

Jean Yoon · Jennifer L. Malin · May Lin Tao ·
Diana M. Tisnado · John L. Adams · Martha J. Timmer ·
Patricia A. Ganz · Katherine L. Kahn

## Abstract

*Purpose*   This study examines the burden of symptoms by treatment type and patient characteristics in a population-based sample of newly diagnosed breast cancer patients.
*Methods*   Using the Los Angeles County SEER Registry Rapid Case Ascertainment, we identified a cohort of breast cancer patients in 2000 and conducted telephone surveys in English and Spanish among participants.

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*Results*   We completed interviews of 1,219 breast cancer patients and found almost half (46%) had at least one severe symptom (any of the following: nausea/vomiting, arm problems, hot flashes, vaginal dryness, difficulty sleeping) that interfered with her daily functioning or mood. Multi-variate analysis controlling for patient characteristics and treatment showed that older (OR = 0.90; $P < 0.000$), black (OR = 0.50; $P < 0.000$), Hispanic Spanish-speaking (OR = 0.37; $P < 0.000$), widowed or never married (OR = 0.68; $P = 0.049$), and working (OR = 0.72; $P = 0.024$) women were less likely to report severe symptoms than other women. Number of comorbid conditions (OR = 1.21; $P < 0.000$) and receipt of chemotherapy (OR = 1.48; $P = 0.040$) were positively associated with reporting symptoms.
*Conclusion*   These findings estimate the prevalence of several mutable symptoms in breast cancer patients that can be addressed by appropriate treatments. Comorbidity is a significant predictor of symptoms, especially amongst those receiving chemotherapy. Variation in symptom reporting occurred by race/ethnicity and other sociodemographic characteristics, raising questions of different thresholds for reporting symptoms or truly fewer symptoms for some sociodemographic groups. Population-based estimates of the probability of symptoms in women with incident breast cancer can be used to provide patient education about potential outcomes following the treatment of breast cancer.

## Introduction

Mortality from breast cancer has steadily decreased since 1990 due to advances in treatment and early detection with 5-year survival rates now 98% for local-stage disease and

81% for regional-stage disease [1]. Given this progress in survival rates, optimizing the quality of life of cancer survivors is paramount. Quality of life or overall well-being is often measured by physical or mental functioning, subjective measures, or presence of symptoms [2]. A number of studies have evaluated the quality of life of selected breast cancer survivors and have generally found that women's global quality of life is very good after breast cancer treatment, regardless of the type of surgery [3, 4]. While these studies provide reassurance that women who survive a breast cancer diagnosis may have good quality of life, it is not well understood how quality of life for breast cancer patients varies for diverse populations as research with population-based datasets has been limited. A recent population-based study examined quality of life variation among women receiving treatment for breast cancer in Los Angeles and Detroit using various domains of functioning, although the study did not look at specific physical symptoms other than fatigue [5].

Global measures of quality of life may not be sensitive to the particular issues that affect breast cancer survivors. A number of studies have found that breast cancer survivors report a number of symptoms and these vary according to the treatment received. Tamoxifen and chemotherapy have been associated with hot flashes in several randomized and observational studies [6, 7]. Chemotherapy has also been previously linked to several other symptoms such as fatigue, nausea, and vaginal dryness as well as a greater number of symptoms [8–11]. Other studies have shown the association between mastectomy and arm problems such as edema and other arm morbidity [12–15]. Finally, research has shown that prevalent symptoms associated with radiation therapy included arm edema, fatigue, skin changes, sleep difficulties, sensory changes, and breast edema [16].

It is not well understood what other factors may influence patients' symptoms following their breast cancer treatment. A number of patient characteristics have been identified that may mediate patients' experience of symptoms following breast cancer treatment including low education [17], marital status [18], age [19, 20], and comorbidiy [21].

The evidence regarding a relationship between symptoms and quality of life and race/ethnicity has been mixed. One study found that white women had greater symptom severity than other women [22]. Another found post-surgical arm edema was increased for black women after controlling for treatment and other demographic characteristics [23], while a study of long-term breast cancer survivors in California found that ethnicity was not associated with overall quality of life [24].

Understanding the relationships between patient demographics and symptoms can help to identify patients who may require special attention following breast cancer treatment, identify patient characteristics linked to susceptibility to various symptoms, or represent a marker for the quality of medical care patients receive.

We studied a diverse, population-based sample of women with incident breast cancer from Los Angeles County to better understand what factors identify patients at greatest risk for symptoms that can impact quality of life following their initial cancer therapy. We focus on several prevalent symptoms that are common following treatment for breast cancer—nausea/vomiting, difficulty sleeping, arm problems, vaginal dryness, and hot flashes—and examine the medical and demographic correlates of these symptoms. We focus on these symptoms as measures of quality of life because providers are able to diagnose and treat these symptoms during routine medical care. As all of these symptoms have potentially effective treatments, our results can have important implications for the health care of women with breast cancer [25–30].

## Methods

The Los Angeles Women's Study (LAW) is a population-based, longitudinal, observational study of women with breast cancer 50 years and older in Los Angeles County. The sample was drawn from a census of incident breast cancer cases diagnosed from March through November of 2000 excluding Asian women 55–70 years who were already allocated to a separate study. Using the Los Angeles County SEER Rapid Case Ascertainment (RCA) program from 103 hospitals or settings in Los Angeles County, we identified 2,745 patients who appeared to meet study criteria. Of these, 215 were unable to be contacted, 224 did not meet study inclusion criteria, 333 were ineligible for patient survey, and 704 refused to participate in a 90-min, baseline computer-assisted telephone interview (CATI) for a participation rate for eligible and contacted patients of 64% (see Fig. 1). About 1,219 patients completed the baseline survey a mean of 223 days after diagnosis (median 185 days, interquartile range 159–255). Both the RAND and UCLA IRB committees approved the study protocol. Participants provided verbal informed consent as part of the telephone interview.

The survey systematically queried each woman about her experiences from diagnosis to the date of the CATI. The survey underwent cognitive testing with 50 women during the early phases of development, later underwent
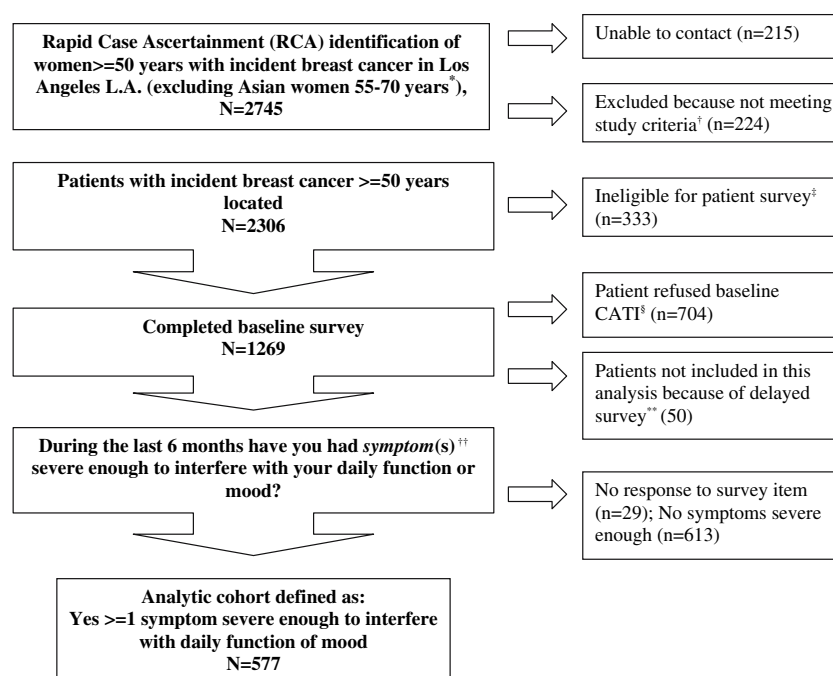
**Rapid Case Ascertainment (RCA) identification of women>=50 years with incident breast cancer in Los Angeles L.A. (excluding Asian women 55-70 years[*]), N=2745**

Unable to contact (n=215)

Excluded because not meeting study criteria[†] (n=224)

**Patients with incident breast cancer >=50 years located N=2306**

Ineligible for patient survey[‡] (n=333)

**Completed baseline survey N=1269**

Patient refused baseline CATI[§] (n=704)

Patients not included in this analysis because of delayed survey[**] (50)

**During the last 6 months have you had *symptom*(s)[††] severe enough to interfere with your daily function or mood?**

No response to survey item (n=29); No symptoms severe enough (n=613)

**Analytic cohort defined as: Yes >=1 symptom severe enough to interfere with daily function of mood N=577**

Fig. 1 Flow chart of analytic sample. [*]Asian women 55–70 years were not available for this study as they had already been assigned to a different study protocol. [†]224 patients identified by Rapid Case Ascertainment were excluded for the following reasons: male gender (5), false positive pathology (1), breast cancer diagnosis later than study window (17), no breast cancer diagnosis (62), breast cancer not incident (139). [‡]333 patients identified by Rapid Case Ascertainment were not eligible for patient survey for the following reasons: physician indicated survey contact with patient could adversely effect patient (usually for mental health reasons, 16), patient did not live in or receive care in Los Angeles County (other than diagnosis-19), patient was deceased and could not be surveyed (81), patient had clinical problem precluding self-report survey (severe dementia-52, hearing impairment unable to be surveyed by phone despite several attempts using technology for hearing impaired calls-29, too ill with medical problems-39), patient spoke neither English not Spanish-the two languages in which the survey was fielded (97). [§]704 patients refused survey participation (of 1,590 eligible) including 420 who refused at baseline survey and the remaining 284 who could not be located at baseline but finally refused at follow-up survey 2 years after diagnosis. [**]50 patients completed the baseline survey at 24 months post-diagnosis, rather than at the time of the baseline survey fielding. Their symptom data will be described in a subsequent manuscript in association with the follow-survey data 24 months after diagnosis. [††]Symptoms were asked about individually including: hot flashes, difficulty sleeping, arm problems, vaginal dryness, nausea, and vomiting

several rounds of pilot testing and review with audiotapes of these interviews by physician investigators prior to fielding the final survey, and finally underwent forward and backward translation into Spanish.

Women were queried about the presence of morbid symptoms and treatment for these symptoms using questions adapted from a previous study of another chronic condition [31]. Specifically, each patient was asked if during the last 6 months she had any of the following symptoms *severe enough that it interfered with her daily mood or function*: arm problems (defined as weakness, numbness, arm swelling, arm pain, loss of arm movement, or other arm problem on the side of surgery), nausea and vomiting, hot flashes, vaginal dryness, and problems with sleep. If she responded yes, then she was categorized as having a severe symptom. We restricted this analysis to patient complaint of severe symptoms as severity is known to predict health status. Additionally, each woman

was asked about treatments received and whether she completed the treatment or was still receiving treatment. The most extensive surgery was considered the primary surgical treatment for the cancer. Women who received a lumpectomy were further categorized as either having an axillary lymph node dissection (ALND) or not having ALND (the no ALND group included women who had sentinel lymph node biopsy only). The survey also queried respondents about age, race/ethnicity, education, total household income from work and non-work sources, marital status, employment status, insurance coverage, and comorbid conditions (see Table 1). Language was determined based upon the woman's choice to complete the survey in English or Spanish. Approximately 50% of responding Hispanic patients completed the survey in Spanish and the remainder completed the survey in English. Stage at diagnosis was obtained from the SEER registry.

**Table 1** Sample patient characteristics ($n = 1{,}219$)

| | All patients n (%) |
|---|---|
| Age | |
| 50–59 | 416 (30) |
| 60–64 | 198 (15) |
| 65–74 | 349 (29) |
| 75–99 | 256 (26) |
| Race | |
| Black | 112 (12) |
| Hispanic English speaker | 103 (8) |
| Hispanic Spanish speaker | 104 (9) |
| Other | 66 (6) |
| White | 834 (65) |
| Education | |
| Less than college | 461 (40) |
| Some college | 376 (31) |
| College graduate | 180 (14) |
| Post-graduate | 202 (15) |
| Income | |
| <$20K | 288 (27) |
| $20K–39K | 244 (22) |
| $40K+ | 687 (51) |
| Working | |
| Not working | 818 (70) |
| Working | 401 (30) |
| Marital status | |
| Married | 625 (48) |
| Divorced | 210 (17) |
| Never married | 88 (7) |
| Separated | 34 (3) |
| Widowed | 262 (25) |
| Insurance | |
| Private/VA | 638 (47) |
| Medicare | 484 (44) |
| Medi Cal/other government | 14 (1) |
| Other | 33 (3) |
| None | 50 (4) |
| 0 | 223 (17) |
| 1 or more | 967 (83) |
| Stage at diagnosis | |
| Unknown | 122 (11) |
| In situ | 173 (13) |
| I | 487 (38) |
| II | 368 (30) |
| III | 50 (5) |
| IV | 19 (2) |

## Analytical methods

We conducted bivariate and multi-variable analyses to study the relationship between patient characteristics and symptom prevalence. Multi-variate analyses were conducted using a two-part model. First, we used logistic regression to predict women experiencing any symptoms severe enough to influence function or mood during the last 6 months. Next, we used linear regression to predict the number of symptoms experienced. We also conducted separate logistic regressions predicting each of the five individual symptoms. Model covariates were the same as the model predicting experience of any of the aggregate five symptoms.

We applied the regression to 1,161 women who participated in the CATI interview and had no missing variables, as well as to six subcohorts defined according to treatment received for the incident breast cancer. These cohorts were specified as women treated with and without chemotherapy (36% vs. 64%, respectively), with and without radiation therapy (54% vs. 46%), and with and without mastectomy (32% vs. 68%). Model covariates included all covariates from the full cohort models as well as interactions between treatments. We also tested for interaction of age with all other predictors and did not find any significant interactions. Covariates predicted dependent variables similarly across the cohorts as presented in Appendix.

Inclusion of hospital characteristics (associated with the site where the patient had her first surgery) had little impact on our multi-variate regression results, so we present only the models without hospital variables.

All regressions were adjusted for clustering within hospital cancer registry that reported the diagnosis to the Los Angeles County SEER Registry [32]. Bivariate and multi-variate results are weighted with non-response weights developed using logistic regression of patient with incident breast cancer noted in RCA file as a function of age, race, stage at diagnosis, and hospital indicators. Comparison of respondents and non-respondents showed that women who were non-white ($P < 0.0001$), were older ($P < 0.0001$), and had a stage III or IV diagnosis ($P < 0.0001$), were less likely to respond to the survey. There were no differences in response by hospital indicators.

## Results

The study sample was racially diverse with 35% of the sample non-white (Table 1). A majority of this sample of women age 50 and older were not working, and many were covered by Medicare. Most of the women had at least one comorbid condition, and breast cancer diagnosis in later stages was infrequent.

Almost half of 1,219 breast cancer patients studied (46%) had at least one severe symptom that interfered with her daily functioning or mood during the first 6 months

**Table 2** Type of severe symptom by treatment received (n = 1,219)

| Treatment | n | At least one symptom (n = 577) | Hot flashes (n = 248) | Difficulty sleeping (n = 353) | Arm problems (n = 138) | Vaginal dryness n = 148 | Nausea, vomiting (n = 158) |
|---|---|---|---|---|---|---|---|
| *% Patients with each symptom* | | | | | | | |
| Mastectomy[a] | | | | | | | |
|    Radiation[b] | 44 | 61 | 25 | 35 | 37 | 13 | 24 |
|    No radiation[c] | 329 | 51 | 18 | 27 | 17 | 12 | 13 |
|      Chi-square *P*-value | | 0.1034 | 0.1337 | 0.3076 | 0.0003 | 0.5213 | 0.0223 |
| Lumpectomy[d] | | | | | | | |
|    Radiation[e] | 596 | 41 | 18 | 26 | 8 | 9 | 10 |
|    No radiation[f] | 315 | 56 | 24 | 34 | 13 | 16 | 16 |
|      Chi-square *P*-value | | <0.0001 | 0.0306 | 0.0060 | 0.0185 | 0.0019 | 0.0100 |
|    Axillary lymph node dissection[g] | 610 | 53 | 21 | 31 | 16 | 12 | 17 |
|    No ALND[h] | 580 | 38 | 17.5 | 24.8 | 5.7 | 10.7 | 6.5 |
|      Chi-square *P*-value | | <0.0001 | 0.0696 | 0.002 | <0.0001 | 0.4073 | <0.0001 |
| Both chemo and rad received[i] | | | | | | | |
|    Chemo and rad completed | 85 | 55 | 25 | 33 | 22 | 15 | 24 |
|    Only chemo completed | 48 | 69 | 17 | 35 | 13 | 12 | 36 |
|    Only rad completed | 30 | 62 | 26 | 35 | 9 | 22 | 32 |
|    Neither completed | 20 | 58 | 36 | 38 | 20 | 15 | 35 |
| Rad only (in Progress/completed)[j] | 477 | 34 | 16 | 23 | 6 | 7 | 3 |
| Chemo only (in Progress/completed)[k] | 259 | 64 | 26 | 39 | 14 | 17 | 27 |
|    Neither[l] | 300 | 41 | 15 | 23 | 12 | 11 | 4 |
|      Chi-square *P*-value[m] | | <0.0001 | <0.0001 | <0.0001 | <0.0001 | <0.0001 | <0.0001 |
| Tamoxifen[n] | 658 | 41 | 19 | 26 | 11 | 9 | 7 |
| No tamoxifen[o] | 642 | 52 | 19 | 30 | 11 | 14 | 18 |
|    Chi-square *P*-value | | <0.0001 | 0.8785 | 0.0184 | 0.7646 | 0.0018 | <0.0001 |
| **All patients** | 1,219 | 46 | 19 | 28 | 11 | 12 | 12 |

[a] Mastectomy regardless of prior lumpectomy

[b] 92% of patients had ALND, 57% had TAM and 85% had chemotherapy

[c] 73% of patients had ALND, 56% had TAM and 42% had chemotherapy

[d] Lumpectomy with no subsequent mastectomy

[e] 40% of patients had ALND, 61% had TAM and 21% had chemotherapy

[f] 57% of patients had ALND, 36% had TAM and 45% had chemotherapy

[g] 53% had TAM and 38% had chemotherapy

[h] 58% had TAM and 10% had chemotherapy

[i] 87% had ALND

[j] 58% had ALND

[k] 88% had ALND

[l] 60% had ALND

[m] Chi-square tests differences between all combinations of chemotherapy and radiation treatment

[n] 23% of patients had chemotherapy

[o] 48% of patients had chemotherapy

following diagnosis. Most of these patients (78%) had fewer than three symptoms. The most prevalent symptoms reported were difficulty sleeping (28%) and hot flashes (19%) (see Table 2). Arm problems were more prevalent among women who had both a mastectomy and radiation compared to mastectomy without radiation or lumpectomy. Women who completed or were undergoing treatment with both radiation and chemotherapy experienced all five symptoms more often than those who had neither treatment (all $P < 0.0001$). The prevalence of these symptoms also varied according to whether treatment was ongoing or completed. For patients undergoing both chemotherapy and radiation therapy, patients were more likely to experience hot flashes, difficulty sleeping, and nausea or vomiting compared to symptom prevalence following these treatments (all $P = <0.0001$).

Bivariate analyses showed variation in the prevalence of any severe symptom by patient characteristics other than treatment. Younger women reported a much greater prevalence of symptoms than older women with 71% of women in the youngest group (50–59 years) reporting severe symptoms compared to 22% of women in the oldest group (75 years and older) ($P < 0.001$). Fewer black women reported any symptoms compared to the other racial/ethnic groups in the study ($P = 0.06$). Women in the highest income group ($P = 0.0002$) and women who were working ($P = <0.0001$) reported higher rates of symptoms. Women who were widowed had fewer number of reported symptoms compared to married women ($P < 0.0001$). There was also a greater reported prevalence of symptoms among women receiving private insurance ($P < 0.0001$). Having a comorbid condition was associated with symptom report ($P = 0.014$) (Table 5).

Multi-variate analysis controlling for patient characteristics and treatment showed that age, race/ethnicity, marital status, number of comorbid conditions, and receipt of chemotherapy were independently related to patient report of any symptoms (Table 3). As in the bivariate analysis, younger women had greater odds of describing severe symptoms ($P < 0.001$) even when controlling for treatment received. Non-white women were less likely than white women to report severe symptoms. Black women were half as likely ($P < 0.001$) and Hispanic Spanish-speaking women were more than 60% less likely ($P < 0.001$) to report symptoms compared to white women. Women who were widowed or never married were significantly less likely than married women to report symptoms ($P = 0.05$). After controlling for covariates, women who were working were less likely to report symptoms than women who did not work ($P = 0.024$). The number of comorbid conditions was also positively related to having any symptoms: an increase in one comorbid condition was associated with a 21% increase in the odds of reporting a symptom ($P < 0.001$).

**Table 3** Multi-variate analysis of predictors for having any severe symptoms (n = 1,161)

|  | Odds ratio [95% confidence interval] |
| --- | --- |
| Age | 0.90 [0.87, 0.92]* |
| Race |  |
|   Black | 0.44 [0.30, 0.64]* |
|   Hispanic English speaker | 0.66 [0.34, 1.25] |
|   Hispanic Spanish speaker | 0.34 [0.20, 0.57]* |
|   Other | 0.44 [0.22, 0.89]** |
|   White | 1.00 |
| Education |  |
|   Less than college | 0.92 [0.62, 1.34] |
|   Some college | 0.90 [0.63, 1.29] |
|   College graduate | 0.80 [0.50, 1.26] |
|   Post-graduate | 1.00 |
| Income |  |
|   <$20K | 1.59 [0.99, 2.55] |
|   $20K–39K | 1.29 [0.85, 1.96] |
|   $40K+ | 1.00 |
| Working |  |
|   Not working | 1.00 |
|   Working | 0.74 [0.56, 0.97]** |
| Marital status |  |
|   Married | 1.00 |
|   Divorced/separated | 1.04 [0.72, 1.50] |
|   Never married | 0.56 [0.33, 0.96] |
|   Widowed | 0.63 [0.44, 0.91]** |
| Insurance |  |
|   Insured | 1.12 [0.52, 2.43] |
|   Uninsured | 1.00 |
|   Number of comorbidities | 1.21 [1.10, 1.33]* |
| Surgery |  |
|   Lumpectomy with ALND | 1.26 [0.62, 2.56] |
|   Lumpectomy without ALND | 0.63 [0.31, 1.28] |
|   Mastectomy | 1.00 |
| Chemotherapy |  |
|   Yes | 1.33 [0.82, 2.17]** |
|   No | 1.00 |
| Radiation |  |
|   Yes | 0.61, 2.88] |
|   No | 1.00 |
| Tamoxifen |  |
|   Yes | 0.93 [0.63, 1.37] |
|   No | 1.00 |
| Stage at diagnosis |  |
|   I | 0.75 [0.48, 1.18] |
|   II | 0.79 [0.45, 1.38] |

**Table 3** continued

|  | Odds ratio [95% confidence interval] |
|---|---|
| III | 0.91 [0.42, 1.97] |
| IV | 0.16 [0.04, 0.60]** |
| Unknown | 0 [52, 2.88] |
| In situ | 1.00 |

* $P < 0.05$

** $P < 0.01$

*** $P < 0.001$

Separate multi-variate regressions for the presence of the five symptoms showed that demographic characteristics predicting any symptom were generally consistent across the five symptoms. Women who had a mastectomy were almost five times as likely to report having arm problems as women with only a lumpectomy. Women who received chemotherapy were more than five times as likely to experience nausea/vomiting than those who did not while tamoxifen use was associated with lower odds of reporting this symptom. No treatments were significantly associated with vaginal dryness.

## Discussion

With diagnosis occurring at earlier stages, increased survival rates, and more patients receiving indicated treatments, the focus of patient and clinician alike often turn to how the cancer or treatment is likely to influence health-related quality of life. We used a diverse, multi-ethnic, multi-lingual population-based cohort of women with incident breast cancer in Los Angeles County to learn population-based rates of five prevalent symptoms mutable with appropriate medical care.

Almost half of all patients had at least one key symptom severe enough to interfere with mood or function, but symptom prevalence varied with treatment(s). After adjustment for stage at diagnosis and treatment, several patient-reported demographics predicted patients reporting symptoms severe enough to affect daily function or mood. Our results confirm that there is a negative relationship between age and symptoms for older women. Working also appears to play a role in reporting fewer symptoms. Severe symptoms may interfere with a woman's ability to perform her job so that women with more severe symptoms leave their jobs. An alternative explanation is that women who are working may be less likely to think that their symptoms are severe enough to interfere with their functioning or mood.

Symptom reporting did not vary by patient income, education, and insurance status, which contradict other research findings [33]. These characteristics are often to related race/ethnicity, which accounted for large differences in symptom reporting in our results. Compared with white and English-speaking Hispanic women, black, Hispanic Spanish-speaking, and women of other races reported lower odds of symptoms. This result is striking given that black women experience poorer quality and timeliness of breast cancer treatment, and poorer outcomes compared to white women [34–37].

As we accounted for stage and type of treatment, the lower rates of severe symptoms reported by non-white or Spanish-speaking women do not appear related to variations in the initial cancer diagnosis and management. These results raise questions about whether women from different demographic groups vary in their threshold for reporting symptoms or whether they truly have fewer symptoms.

When survey respondents were asked if they had any of the five symptoms, 20% of Spanish-speaking Hispanic respondents answered that they did not know or refused to answer the question for at least one of the five symptoms compared to only 5% of white respondents and 6% of black respondents. Thus, language may have an effect on our measurement of symptoms.

Alternatively, differences in physiology may affect the incidence of severe symptoms by women of different races/ethnicities [38, 39]. Black women were much less likely to report difficulty sleeping, vaginal dryness, and nausea/vomiting than white women but were not less likely to report hot flashes or arm problems. Race/ethnicity may be a surrogate for physiologic characteristics that affect the occurrence of some symptoms, for example, body mass index. Alternatively, women with more competing concerns (such as income, housing) may be less likely to report certain severe symptoms (Table 4).

Previous methodological studies of survey questions have found evidence that whites and Hispanics may not respond similarly. Johnson [40] found qualitative differences in whites' and Hispanics' interpretation of health status questions across multiple health surveys. Hayes and Baker [41] found the reliability and validity of a Spanish language patient satisfaction with communication scale differed significantly from that of the English version. Aday [42] noted Hispanics were more likely to respond ''yes'' to patient satisfaction questions than non-Hispanics, regardless of whether the question indicated greater satisfaction or dissatisfaction [41].

Further research is needed to determine interventions to improve identification and treatment of symptoms from breast cancer treatment for these vulnerable groups. Furthermore, as performance measurement and pay for performance become more of a reality, it is important to consider the theory that language and cultural barriers make it difficult for some individuals to admit to symptoms, even when questioned directly as we did in this

**Table 4** Predictors for having severe symptom

| | Hot flashes (n = 248) | Difficulty sleeping (n = 353) | Arm problems (n = 138) | Vaginal dryness (n = 148) | Nausea vomiting (n = 158) |
|---|---|---|---|---|---|
| Age | 0.89* | 0.91* | 0.92* | 0.90* | 0.92* |
| Race | | | | | |
| Black | 1.08 | 0.49** | 0.98 | 0.31** | 0.29** |
| Hispanic English speaker | 0.52* | 0.68 | 1.28 | 1.12 | 0.98 |
| Hispanic Spanish speaker | 0.69 | 0.52* | 1.09 | 0.88 | 0.49 |
| Other | 0.69 | 0.66 | 1.47 | 0.91 | 1.40 |
| White | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Education | | | | | |
| Less than college | 1.39 | 0.98 | 1.66 | 0.99 | 0.86 |
| Some college | 1.13 | 0.68* | 1.67 | 0.97 | 0.95 |
| College graduate | 0.93 | 0.94 | 1.82 | 0.72 | 1.06 |
| Post-graduate | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Income | | | | | |
| <$20K | 1.34 | 1.34 | 1.12 | 0.84 | 1.17 |
| $20K–40K | 0.98 | 1.25 | 0.95 | 0.94 | 0.98 |
| $40K+ | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Working status | | | | | |
| Working | 0.91 | 0.76 | 0.49** | 0.79 | 0.47*** |
| Not working | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Marital status | | | | | |
| Divorced/separated | 1.09 | 1.21 | 1.46 | 0.45* | 1.68* |
| Never married | 0.92 | 0.59 | 0.55 | 0.41 | 0.22** |
| Widowed | 0.68 | 0.74 | 0.83 | 0.51 | 0.67 |
| Married | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Insurance | | | | | |
| Insured | 0.92 | 0.59 | 1.09 | 1.08 | 1.70 |
| Uninsured | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Number of comorbidities | 1.15* | 1.24* | 1.18** | 1.06 | 1.18* |
| Surgery | | | | | |
| Lumpectomy with ALND | 1.39 | 1.73 | 0.47* | 0.98 | 0.95 |
| Lumpectomy without ALND | 1.27 | 1.40 | 0.09** | 1.71 | 0.91 |
| Mastectomy | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Chemotherapy | | | | | |
| Yes | 1.11 | 1.01 | 0.48** | 1.16 | 3.64** |
| No | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Radiation | | | | | |
| Yes | 1.36 | 1.35 | 1.43 | 1.22 | 1.02 |
| No | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Tamoxifen | | | | | |
| Yes | 1.57* | 1.30 | 0.68 | 0.83 | 0.46* |
| No | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| Stage at diagnosis | | | | | |
| I | 0.90 | 1.12 | 3.24* | 0.99 | 2.26 |
| II | 0.92 | 1.13 | 2.82* | 0.83 | 1.96 |

**Table 4** continued

|  | Hot flashes (n = 248) | Difficulty sleeping (n = 353) | Arm problems (n = 138) | Vaginal dryness (n = 148) | Nausea vomiting (n = 158) |
|---|---|---|---|---|---|
| III | 0.71 | 1.91 | 1.66 | 0.34 | 1.74 |
| IV | 0.37 | 0.29 | 0.64 | 0.25 | 1.47 |
| Unknown | 0.81 | 1.93 | 4.31 | 0.46 | 2.39 |
| In situ | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |

$*P < 0.05$

$**P < 0.01$

$***P < 0.001$

study. If this is the case, then before pay for performance is implemented, it would be useful to educate clinicians about culturally appropriate ways to query patients about their concerns.

Limitations

Our study did not include women < 50 years of age, so our results are not generalizable to younger women with breast cancer. Our sample did not include Asian women between 55 and 70 years of age, so we did not have enough power to make separate estimates for Asian women. There was some response bias in our sample with regards to age, race, and stage at diagnosis; however, all of our results are weighted for non-response, so we do not expect non-response to limit the generalizability of our results. In addition, while our survey was fielded in English and Spanish, we were unable to capture the experiences of patients who did not speak either of these languages. Even among patients who indicated that they could complete the survey in English and Spanish, language barriers may still play a role in measurement bias. We attempted to minimize this by using a telephone survey with experienced, trained interviewers.

While we were unable to take into account the duration of the symptom, we believe that treating severe symptoms can have an impact on quality of life including symptoms for a short duration.

**Conclusions**

The optimal methodology for assessing patient symptoms associated with a cancer treatment regimen would include serial patient assessments so that the patient's changing experiences could be captured as her treatments and symptoms change, and we report here using only baseline survey data. However, we think these data provide useful insights as the RCA methodology allowed us to interview patients soon after diagnosis in an effort to minimize recall bias. While this study looks at symptoms experienced only in the short-term within 6 months of their diagnosis, a follow-up study surveyed women 2 years after their diagnosis, and further analysis will determine what symptoms continue to affect patients long-term.

Understanding the relationship between patient characteristics and symptom prevalence can help inform breast cancer providers and patients about treatment benefits and possible negative effects of treatment. Such understanding may motivate a more systematic screening by providers of severe symptoms among patients at-risk for symptoms, thus opening the door to facilitate the use of effective treatments.

**Appendix**

**Table 5** Severe symptom prevalence by patient characteristics (n = 1,219)

|  | N | At least one severe symptom (%) | Chi-square P-value |
|---|---|---|---|
| Age |  |  | <0.001 |
| 50–59 | 416 | 71 |  |
| 60–64 | 198 | 54 |  |
| 65–74 | 349 | 37 |  |
| 75–99 | 256 | 22 |  |
| Race |  |  | 0.0626 |
| Black | 112 | 43 |  |
| Hispanic English speaker | 103 | 49 |  |

**Table 5** continued

| | N | At least one severe symptom (%) | Chi-square P-value |
|---|---|---|---|
| Hispanic Spanish speaker | 104 | 44 | |
| Other | 66 | 35 | |
| White | 834 | 47 | |
| Education | | | 0.1608 |
| Less than college | 461 | 43 | |
| Some college | 376 | 46 | |
| College graduate | 180 | 47 | |
| Post-graduate | 202 | 50 | |
| Income | | | 0.0002 |
| <$20K | 288 | 41 | |
| $20K–40K | 244 | 41 | |
| $40K+ | 687 | 50 | |
| Working | | | <0.0001 |
| Not working | 818 | 43 | |
| Working | 401 | 53 | |
| Marital status | | | <0.0001 |
| Married | 625 | 53 | |
| Divorced | 210 | 55 | |
| Never married | 88 | 40 | |
| Separated | 34 | 59 | |
| Widowed | 262 | 26 | |
| Insurance | | | <0.0001 |
| Private/VA | 638 | 57 | |
| Medicare | 484 | 32 | |
| Medi-Cal/other government | 14 | 50 | |
| Other | 33 | 50 | |
| None | 50 | 52 | |
| Comorbid conditions | | | 0.0135 |
| 0 | 223 | 51 | |
| 1 or more | 967 | 49 | |
| Stage at diagnosis | | | <0.0001 |
| Unknown | 122 | 47 | |
| In situ | 173 | 48 | |
| I | 487 | 39 | |
| II | 368 | 49 | |
| III | 50 | 80 | |
| IV | 19 | 21 | |

**Table 6** Predictors for number of severe symptoms if any (n = 577)

| | Estimate [SE] |
|---|---|
| Age | –0.04 [0.48]* |
| Race | |
| Black | –0.09 [0.14] |
| Hispanic English speaker | 0.05 [0.14] |

**Table 6** continued

| | Estimate [SE] |
|---|---|
| Hispanic Spanish speaker | 0.22 [0.18] |
| Other | 0.58 [0.24]** |
| White | 0 |
| Education | |
| Less than college | 0.11 [0.12] |
| Some college | –0.04 [0.10] |
| College graduate | 0.13 [0.10] |
| Post-graduate | 0 |
| Income | |
| <$20K | –0.13 [0.13] |
| $20K–40K | –0.18 [0.12] |
| $40K+ | 0 |
| Working | |
| Not working | 0 |
| Working | –0.25 [0.07]* |
| Marital status | |
| Married | 0 |
| Divorced/separated | 0.11 [0.12] |
| Never married | –0.19 [0.12] |
| Widowed | 0.04 [0.12] |
| Insurance | |
| Insured | –0.17 [0.23] |
| Uninsured | 0 |
| Number of comorbidities | 0.07 [.02]** |
| Mastectomy | |
| Yes | 0.02 [0.11] |
| No | 0 |
| Chemotherapy | |
| Yes | 0.04 [0.13] |
| No | 0 |
| Radiation | |
| Yes | 0.01 [0.09] |
| No | 0 |
| Tamoxifen | |
| Yes | 0.03 [0.08] |
| No | 0 |
| Stage at diagnosis | |
| I | 0.28 [0.11]** |
| II | 0.17 [0.15] |
| III | 0.11 [0.23] |
| IV | 0.34 [0.59] |
| Unknown | 0.37 [0.17]** |
| In situ | 0 |

*P < 0.05
**P < 0.0001

**Table 7** Predictors for having any severe symptoms for treatment-specific cohorts

| | OR [P-value] | | | | | |
|---|---|---|---|---|---|---|
| | Yes chemotherapy | No chemo-therapy | Yes radiation | No radiation | Yes mastectomy | No mastectomy |
| Age | 0.87 [<0.000] | 0.91 [0.000] | 0.90 [0.000] | 0.90 [0.000] | 0.89 [0.000] | 0.89 [0.000] |
| Race | | | | | | |
|   Black | 0.45 [0.015] | 0.49 [0.001] | 0.37 [0.000] | 0.59 [0.042] | 0.53 [0.145] | 0.42 [0.000] |
|   Hispanic English speaker | 1.03 [0.948] | 0.42 [0.033] | 0.42 [0.023] | 0.78 [0.529] | 0.58 [0.320] | 0.61 [0.149] |
|   Hispanic Spanish speaker | 0.31 [0.016] | 0.43 [0.009] | 0.37 [0.004] | 0.33 [0.025] | 0.27 [0.011] | 0.42 [0.011] |
|   Other | 0.52 [0.257] | 0.37 [0.035] | 0.39 [0.131] | 0.39 [0.030] | 0.29 [0.030] | 0.57 [0.214] |
|   White | | | | | | |
| Education | | | | | | |
|   Less than college | 0.75 [0.394] | 1.24 [0.393] | 1.10 [0.756] | 1.04 [0.859] | 0.78 [0.413] | 1.30 [0.337] |
|   Some college | 0.91 [0.788] | 0.98 [0.927] | 0.81 [0.380] | 1.14 [0.581] | 0.15 [0.684] | 0.90 [0.627] |
|   College graduate | 0.84 [0.598] | 0.72 [0.250] | 0.72 [0.386] | 0.87 [0.662] | 0.54 [0.151] | 0.96 [0.914] |
|   Post-graduate | | | | | | |
| Income | | | | | | |
|   <$20K | 1.39 [0.400] | 1.64 [0.089] | 1.35 [0.394] | 1.79 [0.055] | 0.45 [0.215] | 1.64 [0.110] |
|   $20K–40K | 1.43 [0.290] | 1.20 [0.446] | 1.07 [0.806] | 1.68 [0.131] | 1.71 [0.136] | 1.12 [0.635] |
|   $40K+ | | | | | | |
| Working | | | | | | |
|   Not working | | | | | | |
|   Working | 0.62 [0.090] | 0.86 [0.487] | 0.75 [0.166] | 0.73 [0.215] | 0.69 [0.216] | 0.77 [0.199] |
|   Marital status | | | | | | |
| Married | | | | | | |
|   Divorced/separated | 1.03 [0.907] | 0.95 [0.831] | 1.06 [0.790] | 0.87 [0.637] | 0.83 [0.616] | 1.04 [0.866] |
|   Never married | 0.41 [0.041] | 0.64 [0.174] | 0.78 [0.527] | 0.29 [0.000] | 0.32 [0.007] | 0.73 [0.361] |
|   Widowed | 0.77 [0.576] | 0.55 [0.016] | 0.50 [0.028] | 0.78 [0.427] | 0.95 [0.893] | 0.52 [0.022] |
| Insurance | | | | | | |
|   Insured | 1.11 [0.801] | 0.91 [0.841] | 0.78 [0.682] | 1.53 [0.142] | 1.91 [0.165] | 0.82 [0.738] |
|   Uninsured | | | | | | |
|   Number of comorbidities | 1.12 [0.231] | 1.24 [0.000] | 1.23 [0.002] | 1.19 [0.017] | 1.15 [0.128] | 1.23 [0.001] |
| Mastectomy | | | | | | |
|   Yes | 0.82 [0.623] | 1.27 [0.555] | 0.27 [0.282] | 0.88 [0.741] | – | – |
|   No | | | | | – | – |
| Chemotherapy | | | | | | |
|   Yes | – | – | 2.44 [0.001] | 1.42 [0.402] | 1.98 [0.186] | 1.48 [0.252] |
|   No | – | – | | | | |
| Radiation | | | | | | |
|   Yes | 0.84 [0.660] | 0.70 [0.216] | – | – | 0.62 [0.704] | 0.66 [0.197] |
|   No | | | – | – | | |
| Tamoxifen | | | | | | |
|   Yes | 0.53 [0.181] | 1.38 [0.501] | 1.10 [0.689] | 0.89 [0.821] | 1.03 [0.947] | 1.58 [0.246] |
|   No | | | | | | |
| Stage at diagnosis | | | | | | |
|   I | $1.71 \times 10^{-8}$ [0.000] | 0.80 [0.346] | 0.61 [0.079] | 1.21 [0.574] | 0.78 [0.571] | 0.86 [0.582] |
|   II | $2.03 \times 10^{-8}$ [0.000] | 0.93 [0.806] | 0.83 [0.648] | 1.05 [0.917] | 0.52 [0.200] | 1.29 [0.455] |
|   III | $2.29 \times 10^{-8}$ [0.000] | – | 0.54 [0.353] | 1.85 [0.311] | 0.69 [0.592] | 1.38 [0.583] |
|   IV | $2.23 \times 10^{-9}$ [0.000] | 0.33 [0.157] | – | 0.25 [0.143] | 0.12 [0.044] | 0.09 [0.004] |
|   Unknown | $1.52 \times 10^{-8}$ [0.000] | 0.80 [0.515] | 0.69 [0.363] | 0.80 [0.587] | 0.50 [0.278] | 0.91 [0.799] |

**Table 8** Predictors for number of severe symptoms if any symptoms for treatment-specific cohorts

| | Estimate [*P*-value] | | | | | |
|---|---|---|---|---|---|---|
| | Yes chemo-therapy | No chemo-therapy | Yes radiation | No radiation | Yes mastectomy | No mastectomy |
| Age | –0.06 [0.000] | –0.04 [0.000] | –0.04 [0.000] | –0.05 [0.000] | –0.05 [0.000] | –0.04 [0.000] |
| Race | | | | | | |
|   Black | –0.51 [0.005] | 0.00 [0.986] | –0.09 [0.678] | –0.28 [0.107] | –0.46 [0.010] | –0.03 [0.881] |
|   Hispanic English speaker | –0.18 [0.312] | 0.19 [0.430] | 0.07 [0.711] | –0.04 [0.862] | –0.10 [0.692] | 0.07 [0.734] |
|   Hispanic Spanish speaker | 0.01 [0.978] | 0.16 [0.479] | 0.17 [0.488] | 0.07 [0.747] | –0.36 [0.144] | 0.52 [0.045] |
|   Other | 0.54 [0.079] | 0.30 [0.392] | 0.14 [0.596] | 0.89 [0.013] | 0.76 [0.067] | 0.33 [0.230] |
|   White | Omit | Omit | Omit | Omit | Omit | Omit |
| Education | | | | | | |
|   Less than college | –0.04 [0.859] | 0.18 [0.212] | –0.06 [0.700] | 0.32 [0.025] | 0.20 [0.347] | 0.07 [0.582] |
|   Some college | –0.37 [0.044] | 0.23 [0.144] | –0.04 [0.825] | 0.02 [0.859] | –0.15 [0.469] | 0.07 [0.581] |
|   College graduate | –0.05 [0.806] | 0.17 [0.356] | –0.09 [0.605] | 0.31 [0.029] | 0.26 [0.229] | –0.04 [0.746] |
|   Post-graduate | Omit | Omit | Omit | Omit | Omit | Omit |
| Income | | | | | | |
|   <$20K | –0.13 [0.510] | 0.00 [0.999] | 0.06 [0.740] | –0.24 [0.183] | –0.03 [0.859] | –0.08 [0.630] |
|   $20K–40K | –0.14 [0.471] | –0.08 [0.512] | –0.08 [0.545] | –0.09 [0.501] | –0.12 [0.447] | –0.03 [0.853] |
|   $40K+ | Omit | Omit | Omit | Omit | Omit | Omit |
| Working | | | | | | |
|   Not working | Omit | Omit | Omit | Omit | Omit | Omit |
|   Working | –0.26 [0.020] | –0.17 [0.209] | –0.19 [0.210] | –0.26 [0.027] | –0.18 [0.246] | –0.22 [0.057] |
| Marital status | | | | | | |
|   Married | Omit | Omit | Omit | Omit | Omit | Omit |
|   Divorced/separated | 0.04 [0.784] | 0.09 [0.637] | 0.15 [0.431] | –0.02 [0.902] | 0.17 [0.328] | 0.06 [0.697] |
|   Never married | –0.48 [0.055] | –0.19 [0.290] | –0.10 [0.600] | –0.6 [0.004] | –0.32 [0.176] | –0.29 [0.089] |
|   Widowed | –0.35 [0.045] | 0.11 [0.540] | –0.23 [0.153] | 0.24 [0.199] | 0.05 [0.829] | –0.08 [0.618] |
| Insurance | | | | | | |
|   Insured | –0.19 [0.527] | –0.15 [0.490] | 0.13 [0.542] | –0.47 [0.105] | –0.23 [0.504] | 0.06 [0.735] |
|   Uninsured | Omit | Omit | Omit | Omit | Omit | Omit |
|   Number of comorbidities | 0.12 [0.007] | 0.06 [0.065] | 0.10 [0.004] | 0.06 [0.103] | 0.09 [0.071] | 0.07 [0.029] |
| Mastectomy | | | | | | |
|   Yes | –0.26 [0.174] | –0.00 [0.984] | –0.62 [0.213] | 0.05 [0.762] | – | – |
|   No | Omit | Omit | Omit | Omit | – | – |
| Chemotherapy | | | | | | |
|   Yes | – | – | 0.23 [0.277] | –0.05 [0.836] | –0.48 [0.063] | 0.36 [0.162] |
|   No | – | – | | | | |
| Radiation | | | | | | |
|   Yes | –0.10 [0.567] | 0.06 [0.723] | – | – | –1.15 [0.042] | 0.067 [0.689] |
|   No | | | – | – | | |
| Tamoxifen | | | | | | |
|   Yes | –0.01 [0.979] | 0.16 [0.471] | 0.05 [0.714] | –0.06 [0.777] | –0.12 [0.478] | 0.14 [0.577] |
|   No | – | – | – | – | – | – |
| Stage at diagnosis | | | | | | |
|   I | 0.61 [0.270] | 0.22 [0.057] | 0.15 [0.335] | 0.31 [0.071] | 0.32 [0.183] | 0.23 [0.100] |
|   II | 0.34 [0.494] | 0.24 [0.198] | –0.11 [0.599] | 0.34 [0.137] | 0.46 [0.144] | 0.01 [0.958] |
|   III | 0.31 [0.548] | | –0.31 [0.454] | 0.12 [0.683] | 0.43 [0.187] | –0.60 [0.151] |
|   IV | 1.00 [0.173] | –1.06 [0.003] | | 0.47 [0.388] | 0.38 [0.444] | 0.29 [0.774] |
|   Unknown | 0.38 [0.463] | 0.40 [0.068] | 0.28 [0.212] | 0.24 [0.329] | 0.30 [0.326] | 0.36 [0.060] |

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# Symptom management after breast cancer treatment: is it influenced by patient characteristics?

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**Abstract** *Purpose* With improved patient survival from breast cancer, more interest has evolved regarding the symptoms women experience in association with breast cancer treatments. We studied the extent to which symptoms for women with incident breast cancer are addressed by their physicians and how symptom management varies with patient characteristics.

*Methods* As part of the Los Angeles Women's (LAW) Study, we categorized women from a population-based study of incident breast cancer ($n = 1,219$) as having an unmet need if she had at least one severe symptom (any of the following: nausea/vomiting, arm problems, hot flashes, vaginal dryness, difficulty sleeping) for which she did not receive the help she wanted. Multivariable analyses predicted having any unmet need as a function of patient demographic and health characteristics.

*Results* The prevalence of unmet need varied by the type of symptom with the highest proportion of women receiving help for nausea and vomiting (0.91) and the lowest for vaginal dryness (0.48). Black women (OR = 3.61, 95% CI: [1.57, 8.31]), and Spanish-speaking Hispanic women (OR = 2.69, 95% CI: [1.22, 5.94]) were significantly more likely than white women to report an unmet need. More black and Hispanic women compared to white women cited the doctor not thinking treatment would benefit her ($P = 0.02$), not appreciating how much the problem bothered her ($P = 0.03$), not knowing about treatments ($P < 0.0001$), or insurance/cost barriers ($P = 0.009$) as reasons for her unmet need.

*Conclusion* These results show the persistence of racial disparities in the receipt of appropriate care within the health care system.

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## Introduction

As advances in treatment and early detection and treatment of breast cancer continue to improve patient survival, more

interest has evolved regarding the symptoms women experience in association with breast cancer treatments [1]. The symptoms associated with breast cancer treatment and variations in symptom prevalence as a function of patient characteristics have been well described [2, J. Yoon et al. in preparation]; however, limited evidence exists about patients' assessment of symptom management and how their assessment might vary by patient characteristics.

Most studies on quality of breast cancer care have focused on whether patients received screening, timely diagnosis, and appropriate interventions to treat their cancer [2–4]. These studies have documented undertreatment for older women [5, 6], minority women [7], and women without health insurance [8]. Few studies have looked at symptom management for breast cancer as an aspect of quality of care. Most of those reported have focused on pain management. Pain severity has been reported to be underestimated by physicians more often for black patients than white patients [9]. Across a spectrum of cancer, minority patients appear to receive adequate pain management less often than white patients [10, 11].

Previous research has found that minority breast cancer patients report less symptom severity than white patients [J. Yoon et al. in preparation, 12]. It is also unknown whether minority women receive adequate symptom management for breast cancer as much as white women.

This study examines the extent to which prevalent symptoms for women with incident breast cancer are addressed by their providers and how patient assessment of symptom management varies as a function of race and other patient characteristics. We focus on five symptoms of breast cancer patients—nausea/vomiting, difficulty sleeping, arm problems, vaginal dryness, and hot flashes—which are all potentially mutable with appropriate medical care [13].

## Methods

The Los Angeles Women's Study (LAW) is a population-based, longitudinal, observational study of women aged 50 and older with breast cancer in Los Angeles County. The sample selection is described in the accompanying manuscript [J. Yoon et al. in preparation] and in Fig. 1. Using the Los Angeles County SEER registry Rapid Case Ascertainment from 103 hospitals or other settings in which breast cancer was diagnosed, 1,219 women were surveyed in English or Spanish from 1923 women living in Los Angeles County with incident breast cancer in 2000. Interviews were conducted a mean of 223 days after diagnosis (median 185 days, interquartile range 159–255). Both the RAND and UCLA IRB committees approved the study protocol. Women provided verbal consent to participate in the study.

Survey respondents participated in a 90-min, baseline computer-assisted telephone interview (CATI) for a participation rate of 64%. The survey queried women about the presence of any of the following symptoms *severe enough to interfere with her daily mood or function in the past 6 months*: arm problems (defined as weakness, numbness, arm swelling, arm pain, loss of arm movement, or other arm problem on the side of surgery), nausea and vomiting, hot flashes, vaginal dryness, and problems with sleep. Women who indicated the presence of such symptoms were categorized as having a severe symptom. The survey focused on these symptoms as they are among the most prevalent symptoms experienced by breast cancer patients and all are mutable with appropriate medical care. These symptoms were also selected for inclusion in the survey because they were considered evaluable by patient self-report as compared to a medical record review.

Women with a severe symptom were asked additional questions regarding symptom management. Women's responses indicated whether she wanted help and whether she received the help she wanted for her symptoms. Women with at least one severe symptom who indicated that she did not receive the help she wanted for her symptom were categorized as having an unmet need. These women were asked if the following were reasons why she did not get enough help: the doctor didn't know she had this problem, the doctor didn't think treatment would benefit her at that time, the doctor didn't appreciate how much the problem bothered her, the doctor didn't know about treatments for her problem, the patient wasn't sure she wanted treatment at that time, or her insurance wouldn't pay for the treatment. This analysis describes 448 women with incident breast cancer with at least one symptom severe enough to influence her daily function or mood for which she wanted help.

The survey queried women about her age, race/ethnicity, education, income level, marital status, employment status, and insurance coverage. Language was indicated for Hispanics who took the survey either in English or Spanish. Patients reported treatment with lumpectomy, mastectomy, chemotherapy, radiation therapy, and tamoxifen. Patients' health status was assessed using the SF-12 physical component score (PCS) [14]; comorbidity was assessed using a 14-item list [15], and stage at diagnosis was obtained from SEER registry.

### Analytic methods

Bivariate analyses compared the prevalence of unmet need and reasons for unmet need across various patient characteristics with a chi-square test. Multivariable analysis predicted having at least one unmet need for help with a severe symptom with a logistic regression and included
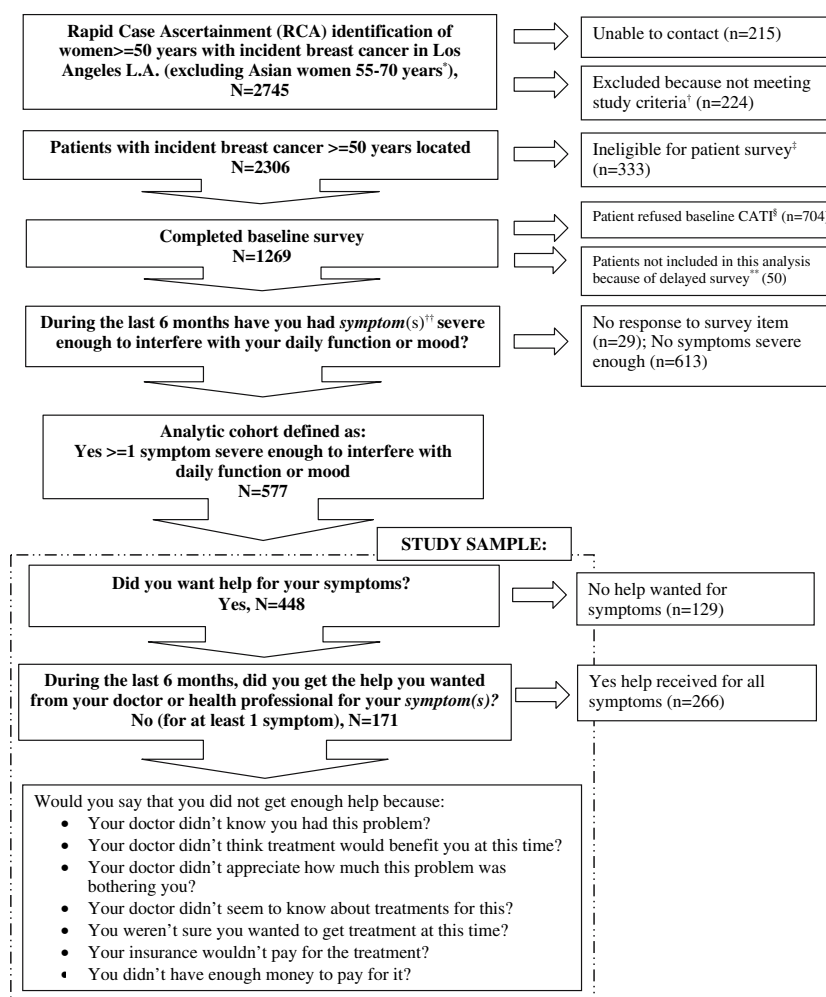
**Fig. 1** Flow chart of analytic sample. * Asian women 55–70 years were not available for this study as they had already been assigned to a different study protocol. [†]224 patients identified by Rapid Case Ascertainment were excluded for the following reasons: male gender (5), false positive pathology (1), breast cancer diagnosis later than study window (17), no breast cancer diagnosis (62), breast cancer not incident (139). [‡]333 patients identified by Rapid Case Ascertainment were not eligible for patient survey for the following reasons: physician indicated survey contact with patient could adversely affect patient (usually for mental health reasons—16), patient did not live in or receive care in Los Angeles County (other than diagnosis—19), patient was deceased and could not be surveyed (81), patient had clinical problem precluding self-report survey (severe dementia—52, hearing impairment unable to be surveyed by phone despite several attempts using technology for hearing impaired calls—29, too ill with medical problems—39), patient spoke neither English nor Spanish—the two languages in which the survey was fielded (97). [§]704 patients refused survey participation (of 1,590 eligible) including 420 who refused at baseline survey and the remaining 284 who could not be located at baseline but finally refused at follow-up survey two years after diagnosis. **50 patients completed the baseline survey at 24 months post diagnosis, rather than at the time of the baseline survey fielding. Their symptom data will be described in a subsequent manuscript in association with the follow-survey data 24 months after diagnosis. [††]Symptoms were asked about individually including: hot flashes, difficulty sleeping, arm problems, vaginal dryness, nausea, and vomiting

patient age, race/ethnicity, income, education, marital status, working status, insurance coverage, number of comorbidities, health status, stage at diagnosis, treatments, and number of severe symptoms as covariates. Multivariable analyses were repeated to predict having an unmet need for help with each of the five severe symptoms individually after adjusting for all the covariates above with the exception of number of severe symptoms.

While there was variation in the time since diagnosis within the sample as some women had completed treatment

and others were still undergoing treatment, we did not find any significant differences in symptom prevalence between women with treatment in progress and women who had completed treatment.

We tested for selection bias of women receiving help for symptoms with a Heckman probit model to account for differences between women who wanted help and women who did not want help for her symptoms [16]. There were no significant effects of selection bias, and we present only the simple model here.

All regressions are adjusted for clustering within hospital registry associated with the diagnosis [17]. Additionally, results are weighted with nonresponse weights developed using logistic regression of patients with incident breast cancer noted in Rapid Case Ascertainment file as a function of age, race, stage at diagnosis and hospital indicators. Comparison of respondents and non-respondents showed that women who were non-white (<0.0001), were older (<0.0001), and had a stage III or IV diagnosis (<0.0001), were less likely to respond to the survey.

## Results

Overall, there were a total of 577 women who reported having at least one of the five symptoms, and it was severe enough that it affected her daily function or mood. Out of these women, 448 wanted help for their symptoms, and 171 reported not receiving wanted help for at least one symptom (Fig. 1). The prevalence of symptoms in the study sample ranged from 11% of women who reported arm problems and vaginal dryness to 28% of women experiencing difficulty sleeping. Most women reporting a severe symptom also reported wanting medical help for her symptom, but the prevalence of wanting help and receiving wanted help varied by symptom (Table 1). Three-quarters of women who reported severe nausea or vomiting reported wanting help for that severe symptom while 91% of those

**Table 1** Severe symptoms and unmet need for help among all patients (n = 1,190)

| | Have severe symptom[a] (%) | Wanted help for symptoms[b] (%) | Received help for symptoms[c] (%) |
|---|---|---|---|
| Difficulty sleeping, n = 353 | 28 | 68 | 70 |
| Hot flashes, n = 248 | 19 | 74 | 51 |
| Nausea or vomiting, n = 158 | 12 | 78 | 91 |
| Vaginal dryness, n = 148 | 11 | 66 | 48 |
| Arm problems, n = 138 | 11 | 77 | 69 |
| Any symptom, n = 577 | 46 | 77 | 75 |

[a] Severe symptoms were defined by self-report as a ''symptom severe enough to interfere with her daily mood or function in the past 6 months''

[b] Percent is calculated as number of patients who wanted help out of those who reported a severe symptom

[c] Percent is calculated as number of patients who received help out of those who wanted help for their severe symptoms

wanting help for nausea/vomiting reported receiving help. In contrast, two-thirds of women who reported severe vaginal dryness reported wanting help for that severe symptom, and 48% of those wanting help received it. Three-quarters of women reporting severe hot flashes reported wanting help for her severe symptom, and 51% of these women reported receiving help for this symptom. For women who had arm problems, 77% wanted help, and 69% of them received help.

### Predicting unmet need

Bivariate analysis showed women with severe symptoms who were 75 years and older reported wanting help and receiving help for severe symptoms less often than younger women (P = 0.0004 and P = 0.04, respectively) (Table 2). Although only one-third of white women and Hispanic

**Table 2** Bivariate analysis of want help for severe symptoms and any unmet need by patient characteristics[a] (n = 436)

| | Wanted help n (%) | Chi-square P-value | Any unmet need n (%) | Chi-square P-value |
|---|---|---|---|---|
| *Age (years)* | | | | |
| 50–59 | 238 (82) | 0.0004 | 92 (39) | 0.0412 |
| 60–64 | 79 (74) | | 28 (36) | |
| 65–74 | 96 (77) | | 37 (38) | |
| 75–99 | 35 (64) | | 14 (46) | |
| *Race* | | | | |
| Black | 39 (78) | 0.6608 | 24 (60) | <0.0001 |
| Hispanic English speaker | 39 (77) | | 13 (32) | |
| Hispanic Spanish speaker | 37 (77) | | 21 (55) | |
| Other | 20 (85) | | 9 (44) | |
| White | 313 (76) | | 104 (34) | |
| *Education* | | | | |
| Less than college | 158 (74) | 0.1271 | 70 (46) | 0.0194 |
| Some college | 137 (76) | | 43 (31) | |
| College graduate | 69 (82) | | 24 (37) | |
| Post graduate | 84 (82) | | 34 (40) | |
| *Income* | | | | |
| Less than $20K | 88 (72) | 0.0367 | 42 (48) | 0.0032 |
| $20–39K | 81 (74) | | 29 (39) | |
| $40K+ | 279 (80) | | 100 (35) | |
| *Working* | | | | |
| Not Working | 276 (76) | 0.5881 | 102 (39) | 0.2938 |
| Working | 172 (78) | | 69 (39) | |
| *Marital status* | | | | |
| Married | 268 (80) | 0.0165 | 97 (38) | 0.0004 |
| Divorced/ separated | 104 (76) | | 51 (48) | |

**Table 2** continued

| | Wanted help n (%) | Chi-square P-value | Any unmet need n (%) | Chi-square P-value |
|---|---|---|---|---|
| Never married | 27 (77) | | 12 (47) | |
| Widowed | 49 (67) | | 11 (22) | |
| *Insurance* | | | | |
| Private and Medicare | 68 (68) | 0.0028 | 25 (36) | 0.0038 |
| Medicare only | 47 (81) | | 20 (48) | |
| Private only | 295 (79) | | 108 (37) | |
| Medical only | 3 (100) | | 1 (31) | |
| Other | 13 (63) | | 8 (66) | |
| None | 22 (85) | | 9 (37) | |
| *Treatment*[b] | | | | |
| Mastectomy | 293 (74) | 0.1807 | 54 (36) | 0.3306 |
| Chemotherapy | 220 (82) | 0.0003 | 78 (35) | 0.0681 |
| Radiation | 235 (75) | 0.1889 | 92 (45) | 0.0202 |
| Tamoxifen | 229 (77) | 0.7213 | 91 (43) | 0.1389 |
| *PCS* | | | | |
| <Mean −1 SD (<41) | 82 (18) | 0.3497 | 38 (18) | 0.0003 |
| Mean ± 1 SD (41–59) | 339 (12) | | 121 (12) | |
| >Mean + 1 SD (>59) | 27 (25) | | 12 (25) | |
| *Number of comorbidities* | | | | |
| 0 | 89 (76) | 0.5764 | 19 (16) | 0.1447 |
| 1 | 114 (80) | | 21 (15) | |
| 2 | 88 (74) | | 13 (11) | |
| 3 or more | 157 (77) | | 29 (14) | |
| *Stage at diagnosis* | | | | |
| Unknown | 13 (55) | <0.0001 | 5 (39) | 0.1186 |
| In situ | 59 (64) | | 25 (44) | |
| I | 176 (83) | | 70 (42) | |
| II | 169 (79) | | 62 (37) | |
| III | 27 (74) | | 9 (36) | |
| IV | 4 (84) | | – | |
| *Number of severe symptoms* | | | | |
| 1 | 185 (65) | <0.0001 | 46 (28) | <0.0001 |
| 2 | 137 (85) | | 62 (45) | |
| 3 or more | 126 (96) | | 63 (41) | |

[a] 12 respondents were not included because they had one or more missing variables

[b] Chi-square tests difference between treatment and no treatment. Treatments are not mutually exclusive

English-speaking women reported at least one unmet need, more than half of black and Hispanic Spanish-speaking women reported an unmet need for at least one symptom (*P* < 0.0001). There was a higher reported rate of unmet need for women reporting low incomes (*P* = 0.003), low

**Table 3** Multivariable predictors of unmet need for help for any symptom[a] (*n* = 436)

| | Odds ratio [95% Confidence Interval] |
|---|---|
| *Age* | 1.03 [0.99, 1.06] |
| *Race* | |
| Black | 3.61 [1.57, 8.31][b] |
| Hispanic English speaker | 0.94 [0.37, 2.38] |
| Hispanic Spanish speaker | 2.69 [1.22, 5.94][b] |
| Other | 1.37 [0.53, 3.57] |
| White | 1.00 |
| *Education* | |
| Less than college | 1.05 [0.46, 2.39] |
| Some college | 0.65 [0.35, 1.21] |
| College graduate | 0.86 [0.36, 2.02] |
| Post graduate | 1.00 |
| *Income* | |
| Less than $20K | 1.67 [0.84, 3.32] |
| $20–39K | 1.22 [0.64, 2.31] |
| $40K+ | 1.00 |
| *Working* | |
| Not working | 1.00 |
| Working | 1.31 [0.79, 2.18] |
| *Marital status* | |
| Married | 1.00 |
| Divorced/separated | 1.25 [0.66, 2.40] |
| Never married | 1.21 [0.45, 3.25] |
| Widowed | 0.24 [0.094, 0.62][b] |
| *Insurance* | |
| Insured | 1.71 [0.66, 4.43] |
| Uninsured | 1.00 |
| *Number of comorbidities* | 0.88 [0.74, 1.04] |
| *Mastectomy* | |
| Yes | 0.93 [0.48, 1.77] |
| No | 1.00 |
| *Chemotherapy* | |
| Yes | 0.66 [0.37, 1.18] |
| No | 1.00 |
| *Radiation* | |
| Yes | 1.21 [0.63, 2.30] |
| No | 1.00 |
| *Tamoxifen* | |
| Yes | 1.18 [0.76, 1.84] |
| No | 1.00 |
| *Health status PCS* | 0.99 [0.96, 1.01] |
| *Stage at diagnosis* | |
| In situ | 1.00 |
| Unknown | 0.98 [0.26, 3.74] |
| I | 0.90 [0.40, 2.03] |
| II | 0.84 [0.36, 1.96] |
| III | 0.67 [0.21, 2.13] |

**Table 3** continued

| | Odds ratio [95% Confidence Interval] |
|---|---|
| *# Severe symptoms* | 1.55 [1.25, 1.93][b] |

[a] Only for women who wanted help for their severe symptoms

[b] Significant at $P < 0.05$

education ($P = 0.02$), those who were divorced or separated or never married ($P = 0.0004$), and those with Medicare only or other insurance ($P = 0.0038$). By type of treatment, women who had chemotherapy were much more likely to want help ($P = 0.003$) than those without chemotherapy, and women with radiation therapy had a higher rate of unmet need ($P = 0.0202$) than those without the treatment. It appeared that unmet need was the lowest for women with the greatest severity of disease as women with the worst health status ($P = 0.0003$) and greatest number of symptoms reported lower rates of unmet need ($P \le 0.0001$).

Multivariable analyses showed that amongst the patient predictors of unmet need for severe symptoms, only race/ethnicity, marital status, and number of severe symptoms were significant. Black women and those who elected to conduct the interview in Spanish were significantly more likely to report an unmet need in association with a severe symptom after adjusting for other patient characteristics (Table 3). Black women were more than three times as likely as white women to report an unmet need while Hispanic Spanish-speaking women were more than twice as likely as white women to report an unmet need. Widowed women had a 57% lower likelihood of reporting an unmet need compared to married women. Multivariable analyses showed the presence of one additional severe

symptom was associated with a 55% higher likelihood of reporting an unmet need. Type of treatment was not an independent significant predictor of unmet need.

While there were differences in reported symptom prevalence by race/ethnicity and differences in unmet need by type of symptom, additional multivariate analyses showed that differences in any unmet need could not be accounted for by racial/ethnic differences in reported symptom prevalence across the five symptoms (data not shown).

Patient report of reasons for unmet need

Amongst the women who specified a reason they believed their doctor or other health care professional did not help her severe problem, the reasons reported varied by symptom (Table 4). For women reporting difficulty sleeping and vaginal dryness, the most frequently cited reason for not receiving wanted help was that her doctor did not know she had this symptom. Among women who reported unmet need for severe hot flashes, most patients reported that her doctor did not think treatment would benefit her, or her doctor did not know about the problem. For women who reported not getting wanted help for severe arm problems, 29% reported her doctor did not appreciate how much the problem bothered her. The proportion of women who offered no reason for not receiving help ranged from 18% of those with nausea or vomiting to 34% of those with hot flashes.

When the reasons for not getting help for any symptom were analyzed by race/ethnicity, more minority women compared to white women cited the doctor did not think treatment would benefit her ($P = 0.02$) (Table 5). Almost one-third of Hispanic Spanish-speaking women and women of other race cited that the doctor did not appreciate how

**Table 4** Reasons for unmet need for help by symptom[a] ($n = 171$)

| | Hot flashes (%)[b] $n = 82$ | Difficulty sleeping (%) $n = 64$ | Arm problems (%) $n = 31$ | Vaginal dryness (%) $n = 47$ | Nausea or vomiting (%) $n = 10$ | Chi-square test *P*-value |
|---|---|---|---|---|---|---|
| Doctor didn't know about problem | 20 | 33 | 25 | 47 | 19 | <0.0001 |
| Doctor didn't think treatment would benefit them | 23 | 7 | 14 | 13 | 29 | 0.0039 |
| Doctor didn't appreciate how much problem was bothering them | 10 | 19 | 29 | 8 | 11 | 0.0052 |
| Doctor didn't know about treatments | 16 | 14 | 14 | 11 | 15 | 0.8466 |
| Weren't sure wanted treatment[c] | 6 | 15 | 0 | 26 | 0 | <0.0001 |
| Insurance wouldn't pay for treatment | 8 | 9 | 18 | 9 | 35 | <0.0001 |
| No reason given | 34 | 30 | 24 | 20 | 18 | 0.2100 |

[a] Respondents were those who wanted help and did not receive it

[b] Column percents do not add to 100%. Respondents listed as many reasons as applicable

[c] All respondents had reported wanting help for her symptoms

**Table 5** Reasons for any unmet need for help by race/ethnicity ($n = 171$)

| | Black (%)[a] $n = 24$ | Hispanic English speaker (%) $n = 13$ | Hispanic Spanish speaker (%) $n = 21$ | Other (%) $n = 9$ | White (%) $n = 104$ | Chi-square test $P$-value[b] |
|---|---|---|---|---|---|---|
| Doctor didn't know about problem | 40 | 27 | 35 | 33 | 31 | 0.7534 |
| Doctor didn't think treatment would benefit them | 23 | 28 | 30 | 61 | 12 | 0.0181 |
| Doctor didn't appreciate how much problem was bothering them | 6 | 15 | 28 | 27 | 14 | 0.0333 |
| Doctor didn't know about treatments | 20 | 8 | 5 | 53 | 11 | <0.0001 |
| Weren't sure wanted treatment[c] | 13 | 23 | 5 | 22 | 16 | 0.273 |
| Insurance wouldn't pay for treatment | 3 | 26 | 10 | 22 | 7 | 0.0085 |
| No reason given | 34 | 29 | 18 | 7 | 40 | 0.0131 |

[a] Column percents do not add to 100%. Respondents listed as many reasons as applicable

[b] Chi-square tests differences between racial/ethnic group for each reason

[c] All respondents had reported wanting help for her symptoms

much the problem bothered her compared to half as many white women ($P = 0.03$). A greater proportion of breast cancer patients who were black and other race as compared with other women believed that her doctor did not know about treatments ($P < 0.0001$). There were significant differences in reporting of insurance/cost barriers ($P = 0.009$) with Hispanic English-speaking women most likely to cite this reason. White women were more likely not to report a reason for not getting wanted help ($P = 0.01$).

## Discussion

Good symptom management may be a key predictor of patients' willingness to continue long-term treatment likely to affect survival. The first step in symptom management is symptom recognition, as providers are able to initiate management strategies only if they are aware the patient has the symptoms. The frequent patient reports of doctors not recognizing the severity of symptoms suggests providers may not be systematically evaluating symptoms and their effects on function and quality of life. Developing systems that could be implemented in oncology practices to routinely and proactively assess patients' symptoms may improve patient outcomes.

The high rate of unmet need for symptom management for vaginal dryness compared to other symptoms suggests less attention is directed towards this symptom for breast cancer patients. Vaginal dryness is associated with natural menopause and is made worse by chemotherapy treatment [18]. Women may be unwilling to bring up this problem with their doctors, and physicians may not be reliably asking about this symptom or related sexual functioning. Both the women and their physicians may not be aware of effective treatments for this symptom as many women with

vaginal dryness who reported not getting help in this study reported that the doctor did not know about the problem or they weren't sure they wanted help. Addressing the management of this symptom is critical to improving patients' quality of life as it has consequences for women's sexual functioning [19, 20].

The most significant predictor of patients' not receiving the help they wanted for their symptoms was race/ethnicity. The greater unmet need among black and Hispanic Spanish-speaking patients compared to white patients may reflect disparities in treatment for minorities and limited English-proficient groups in the health care system overall [21]. Greater unmet need amongst black and Hispanic Spanish-speaking patients is particularly remarkable since it was noted in a related study that these women are less likely to report having symptoms [J. Yoon et al. in preparation]. These studies provide evidence to support that process in health care delivery influences health outcomes.

Several of the reasons cited for not receiving wanted help were specific to doctor–patient communication such as doctor not knowing about the problem, not thinking treatment would benefit the patient, and not appreciating how much the problem bothered the patient. Black and Hispanic patients were more likely to report these communication-specific reasons for their unmet need compared to white patients.

Some of these communication problems may be a result of minority patients being less assertive in interacting with their physicians. One study found that black patients were significantly less likely to ask questions, be assertive, or express concern with their physicians than white patients [22]. However, this same study found that physicians were also less likely to initiate giving information to black patients. Interventions to improve patient–physician communication which focus on the physician may be more

effective as one study of breast cancer care showed that physician-initiated communication was a key factor in patients' perception of having a treatment choice and greater satisfaction with care [23]. Still, other research has found that minority patients report better communication with physicians of concordant race/ethnicity suggesting there may be cultural barriers in non-concordant relationships [24, 25].

Some of the differences in unmet need may be due to the language barrier for patients who are limited English-speaking. Our data show the importance of collecting patient language information as a factor in quality of care as the results for Hispanic English-speaking patients were more similar to non-Hispanic whites than Hispanic Spanish-speaking patients for rates of unmet need and reasons for unmet need. This study supports existing evidence that language barriers can result in worse outcomes for patients [26].

Another concern arising from this analysis is the prevalence of women perceiving their doctors did not know about treatment for her symptoms. While these symptoms cannot always be eliminated, for the most part, the symptoms included in the study can be ameliorated. While some of the racial/ethnic differences in getting help for severe symptoms may be attributable to linguistic barriers, the disproportionate number of black patients who cited that their physician did not know about treatments suggests communication between providers and some patients may be limited by differences in culture and communication or by a lack of trust between patient and clinician [27–30]. Using only patient-self report data, we cannot distinguish whether physicians treating black patients might be less knowledgeable about symptom management than physicians treating other patients or whether differences in communication account for such differences.

Limitations

We believe these results to be the first population-based assessment of the symptom burden and unmet need for patients with incident breast cancer. Although this study relied on patient recall, this study identified patients using Rapid Case Ascertainment (RCA) early in the course of her illness to minimize recall bias. One limitation was that we asked patients whether she had received help for their symptoms, but we did not ascertain the specific type of help (e.g. specific prescription drugs, referrals to specialists, or complementary or alternative therapies). Another limitation is that a woman may have received help and not been aware of it—i.e. she was prescribed a medication for her symptoms but did not recognize that was the purpose of the treatment (e.g., a selective serotonin reuptake inhibitor was prescribed for hot flashes without the patient being aware that was the reason).

While we did not take into account the duration of the symptom, we believe that the experience of severe symptoms can impact quality of life even if the problem is short term.

Our study did not include women less than 50 years of age, so our results are not generalizable to younger women with breast cancer. Our sample did not include Asian women between 55 and 70 years of age, so we did not have enough statistical power to obtain separate estimates for Asian women. Our sample was limited to women in Los Angeles County, so our results may not be generalizable to other areas of the U.S.; however, a strength of this sample is the inclusion of diverse racial/ethnic groups.

It is also unknown if more symptomatic women were less likely to respond to the survey. There was some response bias in our sample with regards to age, race, and stage at diagnosis; however, all of our results are weighted for non-response, so we do not expect non-response to limit the generalizability of our results. While we focused on patient characteristics related to symptom management, we did not examine the associations with physician and practice characteristics that may be contributing to disparities in symptom management.

Another limitation involves the potential changes in symptom management since the survey was conducted. Increased adoption of treatments such as SSRIs to treat hot flashes since 2000 may have had a small effect on racial/ethnic disparities in symptom management.

This analysis adds to the literature by illustrating disparities in symptom management for breast cancer patients. These data also contribute new data regarding mechanisms for disparities. Some patients perceive lack of insurance to be responsible for her not receiving adequate symptom management. Other patients suggest her physician lacks awareness of the symptom, its effects, or its treatments. While steps have been made towards a more equitable system of care [31], research continues to highlight the need to address the multiple causes of suboptimal treatment [32].

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